

**The experiences of Families who have a Child living with Inflammatory Bowel
Disease: Their Stories**

**A thesis submitted in partial fulfillment of the requirements for the Degree of
Master of Science in Child and Family Psychology**

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By

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Key to Transcriptions

Throughout the results section the researcher has used a number of different grammatical symbols to help identify specific points throughout the writing. The key below will help the reader to identify these things;

[] this identifies the author of the quotes that have just been mentioned. In some cases it also identifies words that have been added to the sentence to help the reader to clarify the sentence.

Italics Italics have been used to identify the participants voice, as it is woven throughout the text this helps the reader to easily identify this.

Editorial Style

Throughout this report the researcher has utilized multiple tenses in the text, in order to add depth and meaning to the readers experience. The use of 'I' has been included so that the researcher can include her own thinking and experiences of the study, as well ensuring the reader can clearly define this as an observation or opinion.

Researcher Interest

I have come from a psychology focused degree, with my main focus being children and their families. Having always had an interest in young children I have perused many part time jobs throughout my university life that have enabled me to work closely with this cohort of individuals. Being exposed to many different circumstances it became clear to me early on that I had a real focus and passion about trying to provide better outcomes for individuals and to try to promote equality in all areas of their lives, something that I strived towards constantly in my part time positions.

I was exposed to a story of an old acquaintance one day; she described the struggle her family was faced with once they had left hospital with their sick child. Being left to care for her, provide the medicine and treatment that was all taken care of by the health professionals, and suddenly being all on their own with no immediate professional support. This story inspired my thinking for this thesis, with the wish it will make a small amount of difference in the lives that families of children with inflammatory bowel disease are faced with.

The challenge in this thesis comes from two aspects, the first being the qualitative methodology that has been used, something I have had no prior experience in. Secondly choosing inflammatory bowel disease as the illness for this study, it was something that I had not heard of at the time selecting my thesis topic, and it was not something that was well researched in children. It gave me the opportunity to learn about something new and begin to fill a gap in the research.

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Abstract

Inflammatory bowel disease (IBD) is a disease that is becoming more prevalent in young children, with diagnosis more commonly being made between the ages of 15 and 30 years old. Previous research has focused significantly on the adult cohort, specifically looking at the medical symptoms with very little focus on children and adolescents and the psychological affect that is likely to be present. The focus of the present study was on families living with children who had been diagnosed with IBD and were under the age of 16 years old.

The aim of this study was gain an insight and to hear the stories of these families and their journey with IBD, and to determine if these individuals are affected by psychological symptoms. Four mothers who had children diagnosed with IBD were interviewed using a semi structured interview method to gain insight into their journey. The results indicate that families and children with an IBD diagnosis all experience psychological symptoms as well as challenges within their own family cohort, including comorbid disorders such as anxiety and a family divide when the sick child was chronically ill.

The findings of this study uncovered seven common themes and a number of subthemes relating directly to noticeable changes or challenges that they were faced namely these were; the effect on the child's characteristics, guilt, school, difficulty forming and maintaining relationships, academic difficulty, emotional toll on family, divided family, financial stressors and psychological support. These psychological effects could be due to a number of factors including, the medication that the children are required to take and the developmental stage that they are in.

Future research in this area could further develop this study by gaining perspective from the fathers, siblings and individuals themselves.

Introduction

Inflammatory Bowel Disease (IBD) was once considered to be the disease of the Western world (Shikhare & Kugathasan, 2010). There were much lower reported rates of IBD in Eastern countries; however, emerging data suggests that the disease is showing a rising trend in the Eastern countries (Shikhare & Kugathasan, 2010).

IBD consists of two clinical subtypes: ulcerative colitis (UC) and Chron's Disease (CD) which are chronic inflammatory diseases of the gastrointestinal tract. They are closely related yet they are two distinct and different diseases. The etiology of IBD is considered complex, and although there is no known cause, significant advances in understanding the disease and its cause have been made over the last decade (Shikhare & Kugathasan, 2010). IBD appears to be multifactorial, with changes in lifestyle, diet, host genetic factors, urbanization as well as environmental changes it remains unclear which specific factors are responsible for the rising trend (Shikhare & Kugathasan, 2010).

The incidence of IBD is becoming increasingly more common in children (Heuschkel, 2008). There are multiple published studies that confirm the rising incidence of IBD in children. A Finnish study reported that the incidence of IBD in childhood increased from 5 per 100,000 during 1987 to 15 per 100,000 in 2003 (Qualia & Bousvaros, 2013). Similar findings have also been seen in French and Scottish studies (Qualia & Bousvaros, 2013). About 20% of all IBD patients are made up of individuals under the age of 19 years old; therefore, a substantial burden of this disease is children and young adults (Heuschkel, 2008).

Medical professionals are becoming increasingly aware of the management issues of these young people, due to the fast increasing numbers of young people with this potentially disabling chronic illness (Heuschkel, 2008). It is believed that children and young adults who experience such chronic complex and at times debilitating disease should have access to multidisciplinary support. This team would ideally include a dietitian, psychologist, an IBD specialist nurse and a paediatric gastroenterologist

(Heuschkel, 2008).

UC and CD are directly associated with considerable days lost absent from both school and later in life work (Ananthakrishnan, et al. 2013). There is common comorbidity of psychiatric disorders or symptoms, more frequently being depression and/or anxiety (Ananthakrishnan, et al. 2013). The psychological perspective of the families and the child with IBD, a neglected field of previous research has been associated with many other childhood illnesses in other research (Bannaga & Selinger, 2015; Biedel & Alfano, 2011; Sanderson, 2014). Many areas such as anxiety, depression, and academic achievement have all been well documented in relation to child hospitalization for an array of disease and illness (Bannaga & Selinger, 2015; Biedel & Alfano, 2011; Quinton & Rutter, 1976).

Structure of the thesis

Chapter One; begins with a literature review which provides the reader with an overview of IBD, the prevalence as well some of the effects that IBD and chronic illness can have on individuals and their families. This chapter concludes by providing the rationale for this research.

Chapter two; this chapter will describe the qualitative research methodology for this study. Outlining the interpretative phenomenological analysis (IPA) and as well as defining the method for conducting the research.

Chapter three; the results will be presented in this chapter. Throughout the presentation of the results the researcher will link the findings back to the literature in chapter one and reveal observations and thoughts that the researcher has noted as the study unfolded.

Chapter four; the final chapter of this thesis will be the discussion of the current findings and that of previous research. Research limitations and consideration for future research will be identified.

This study seeks to add to the limited research and literature on the psychological impact

of IBD that is experienced by individuals but also the family as a whole by utilizing a qualitative methodology, interpretative phenomenological analysis (IPA) to analyze the data and to detect and define the relevant themes that emerge. In the past, research that has been conducted has had a strong focus on the adult cohort and the affects that they experience medically as well as physically. This research however, is seeking to gain insight from the parents of children who are living with IBD

What experiences are families faced with when they are living with a child with IBD?

The main research focus of this study is to assess and gain further insight into the experiences of families who have had a child living with IBD. Interviews with the parents of the children will be open-ended, conducted in a way that the participants are able to tell their own unique story, unfolding what they feel comfortable sharing the researcher will direct the interview; rather this will be up to the participants themselves. The initial question will be “can you tell me about your experiences you have had as a family when your child has IBD”.

Throughout the interview process if required, prompt questions may be utilized to encourage the participants to further tell their story or to clarify aspects from the conversation.

Prompt topics may include:

1. Were the needs of you and your child met during your hospital stay?
2. Support that was offered once you left the hospital.
3. Support groups while in hospital for the family, siblings, child.
4. Challenges
5. Supports – what made the situation easier/more bearable.
6. Whether there was help from extended family.
7. Care required

This chapter outlines the incidence of IBD as well as highlighting the high comorbidity of other disorder such as anxiety and depression. Chapter Two explains these points as well as additional comorbidities and challenges in more detail in the literature review.

Chapter 2: Literature Review

The following section reviews the literature that explores the outcomes and experiences that have been associated with a child's diagnosis of IBD and consequently their hospitalisation. Literature on family involvement, developmental effects on children as well as anxiety and fatigue have also been examined with regard to the effects that have been experienced by the family as a whole.

The literature review chapter will be presented under subheadings in order to clearly identify each phenomenon. This was also how the researcher searched the literature as described below.

Electronic databases were used by the researcher to search for the most comprehensive collection of relevant literature. These included Psych Info, PubMed, and Google Scholar. Searches were completed using multiple combinations of keywords, including but not limited to: inflammatory bowel disease, IBD, Chron's disease, CD, ulcerative colitis, UC. Searches were further filtered using terms such as children, effects, hospitalisation, and outcomes. These results were filtered using the terms family, sibling, fatigue, quality of life and QoL.

The researcher limited the results to only include studies published within the past 10 years. This ensured that all referencing was current however in some cases older research was reviewed and included where deemed relevant and insightful.

The electronic searches yielded a large number of results. Studies were selected for inclusion based on relevance to the current study. While the focus of the current study were the experiences of families when a child has IBD and has spent time in hospital due to this disorder, it was also necessary to explore the research about child hospitalisation, effects on siblings and parents or caregivers as well as the psychological outcomes of the phenomenon. To further ensure a complete and comprehensive literature review was obtained, the references for each pertinent article were checked for any other relevant references.

Study Objectives

The objective of the current study was to explore experiences of families who have a child that has been diagnosed with IBD and who has spent time in hospital for this disorder. A further objective of this study however was to extend the current literature in the area of IBD in children, the effects on development, family relations and other areas of family life. Research in this area will help enhance the knowledge of IBD within the medical field and enable the medical practitioners involved to provide care and support for these families that are meeting their needs.

What is Inflammatory Bowel Disorder?

IBD Inflammatory bowel disease (IBD) involves chronic inflammation of all or part of the digestive tract. IBD primarily includes ulcerative colitis (UC) and Crohn's disease (CD). Symptoms will usually include severe diarrhoea, pain, and fatigue and weight loss. IBD can be debilitating and sometimes leads to life-threatening complications (Boirivant & Cossu, 2012; Lemberg & Day, 2015; Moeeni & Day, 2011).

UC is an IBD that causes long-lasting inflammation and ulceration in the innermost lining of the large intestine (colon) and rectum.

CD is a form of IBD that can cause inflammation of the lining of the digestive tract. The inflammation can involve different areas of the digestive tract including the large intestine, small intestine or both (Lemberg & Day, 2015).

A high prevalence of the IBD's, CD and UC are found in the New Zealand population with 155 in 100,000 people being diagnosed with this condition. It is believed that the incidence of UC and CD in children and adolescence are on the rise (Ministry of Health, 2015). There are a number of studies that support this claim that the rate of children being diagnosed with IBD is increasing (Benchimol, et al. 2009; Ministry of Health, 2015; Henderson, et al. 2012). It has also been identified that children are now being diagnosed with IBD at a much younger age. A study conducted by Henderson et al. (2012) found

that the median age of diagnosing IBD had decreased from 12.7 years in the early 1990's to 11.6 years between the years of 2003 to 2008. Canadian research by Benchimol et al. (2009) found that the highest increase in diagnosis was under the age of 5 years old.

There is some controversy around the gender prevalence of IBD however this may be due to the limited data available (Zelinkova, & der Woude, 2014). It is believed that there are different risk factors that can affect each gender differently, as well as the geographic location of the individual (Freeman, 2004). A number of studies suggest that there is a higher prevalence in males however this is variable depending on the studied population showing variations of equal distribution to 2.5:1 (female: male) (Freeman, 2004; Griffiths, 2004; Zelinkova, & der Woude, 2014). Furthermore, there has also been controversy with results relating to gender and IBD related treatments. It is believed that within the CD population male gender is seen as a risk factor for major abdominal surgery, while female gender was seen as requiring higher rates of surgical colon resection (Wagtmans, et al. 2001). UC sufferers have relatively more consistent findings, with males needing higher rates of colon resections and females reported having higher complications after surgery (Rottoli, et al. 2012).

Although IBD can present at any age, approximately 25% of all diagnoses are made in the first two decades of life. Whilst IBD may present at any time within this age group, the highest rates are usually seen in teenage years (Lemberg & Day, 2015). There are however a number of infants and young children who are diagnosed with IBD, CD or UC. Given that CD and UC remain incurable diseases, the diagnosis of these conditions in childhood will impact heavily upon children (and their families) over their lifetimes (Lemberg & Day, 2015).

Children's lives can be significantly affected by IBD, with many frequently being absent from school causing social and academic difficulties, as well as having to attend many medical appointments. As many as 25% of children and adolescents will need emergency medical attention or hospital admission (Bairivant & Cossu, 2012).

Inflammatory Bowel Disease (IBD) symptoms can be chronic, irregular and unpredictable for many individuals. Some of the most common symptoms include abdominal pain, fatigue, weight loss, delayed puberty and diarrhoea. Treatment of these symptoms can be complex and usually requires the modification of an individual's way of life such as dietary modification, more involved treatment plans that include infusions and surgery. These compound the distress and discomfort for the individual.

The severity of the disorder that the individual has been diagnosed with determines the type of surgery that they require. It is believed that as many as 70% of patients with a diagnosis of either CD or UC will require surgery at some stage of their illness (Chron's and Colitis Foundation of America, 2016). Unlike UC, surgery does not cure Chron's disease however it can be used to reduce some symptoms that patients develop. Such surgeries include strictureplasty which widens areas of the bowel; resection or removal of areas of scar tissue in the bowel or colon, and in more severe cases an ileostomy is performed; which is when an opening (called the stoma) is made in the individual's abdomen the ileum is then brought to the surface of the skin and this allows waste to drain into a pouch that is worn on the exterior of the individuals body (Chron's and Colitis Foundation of America, 2016).

Side effects from medications are common due to a large variety of these that are taken to reduce any discomfort or irregularities. Medications can therefore contribute to the burden of the disease with weight gain, acne and depression all being common results from various medications that are prescribed. Given the complex nature of IBD and the effects of the medications, young people who have been diagnosed with IBD are at a significant risk for developing a number of psychological issues that become comorbid with IBD itself. This is especially true for individuals who have a more severe case of IBD.

The cause of IBD is not well understood. It is known however that there is a complex interaction involving several factors, being; genes, the immune system and environmental factors. The gastrointestinal tract in humans would in normal circumstances contain harmful bacteria, with the primary purpose to aid in digestion. The immune system in a

healthy individual attacks harmful bacteria and other organisms, usually at this time the harmless bacteria are protected from the attack (Chron's and Colitis Foundation of America, 2016). In patients with IBD the harmless bacteria are mistaken for foreign invaders and a defence response is triggered, the response produces inflammation of the intestines (Chron's and Colitis foundation of America, 2016). Normally this would subside but in individuals with IBD this does not occur, leading to chronic inflammation, ulceration and thickening of the intestinal walls. Research has been able to identify genes that can be inherited and make an individual susceptible to developing IBD, environmental triggers are however unknown (Chron's and Colitis foundation of America, 2016).

Child Hospitalisation

Child hospitalisation can be a traumatic and stressful time for all individuals involved. Even a relatively short stay can inflict a great deal of stress and anxiety on the child as well as the parents or caregivers. Independent of the illness, the process of hospitalisation itself may produce a stressful environment for both the individual and the family. There is strong evidence to suggest that hospitalisation is a stressful event and that it frequently leads to diminished ability, developmental inequality, lower self-esteem and externalisation of emotions, in turn this can lead to a lessened ability to cope with stressful or adverse life events (Bolig & Weddle, 1988; Skipper & Leonard, 1968). As well as effects that directly impact on the child, caregivers are also impacted and can experience feelings of distress due to the loss of control in the situation that they are faced with. This distress does not necessarily lessen relating to the acuity of the illness, rather, the parents will be faced with this regardless of the diagnosis or acuity (Franck, et al., 2015; Whelan & Kirkby, 2000).

Despite the medical professionals attempts to make a child's stay as comfortable and as stress free as possible, it is common for parents or caregivers involved to rate their anxiety levels far higher than the child patients during this time (Whelan & Kirkby, 2000). This anxiety can have detrimental effects on the child. The emotional contagion

hypothesis explains this significant increase in the emotion as the transference of emotions from the caregiver to the child, this happens without awareness of either individuals (Whelan & Kirkby, 2000).

Over the past 20 years there has been a considerable shift in the care provided in hospitals as well as a reduction in the number and length of admissions especially in children. Other changes include less restrictions surrounding visitors and visiting hours, with many hospitals now providing space for children who are able to play, and parents are encouraged to stay in hospital with their child. A number of minor illnesses or surgeries now only require a child to be seen as an outpatient which makes the experience less traumatic and stressful for them (Wilson, et al, 2010). Stressful experiences have been identified by a number of researchers as contributing to negative hospital experiences (Wilson, et al, 2010; Whelan & Kirkby, 2000). Such experiences include painful procedures, being extremely unwell, the unknown hospital environment, reduced physical activity, depending on people who are strangers to the child, anxiety over missing school, and being separated from friends and family (Wilson, et al, 2010).

Melnyk (2000) completed a literature review of studies that documented the outcomes of children who had been hospitalised. The studies highlighted characteristics that developed in hospitalized individuals such as regression, separation anxiety, sleep disturbances and emotions such as sadness and apathy. It was also noted that these behaviours and characteristics could persist for months and sometimes years in individuals particularly in children who have repeated hospital stays or continued treatment (Wilson, et al. 2010).

Factors that contribute to negative reactions in parents and caregivers have been given little attention in the research. These can cause additional adverse reactions in the child such as; anxiety, depression, sleep disturbance and loss of appetite. Both hospitalization of a child and stress detected in parents (or caregivers) can lead to a number of outcomes including feelings of loneliness, grief, abandonment, and the intense need for love, affection and maternal protection (Skipper & Leonard, 1968).

Skipper & Leonard (1968) identified that children who had regular supportive

communication and contact with a familiar nurse or constant family support during their stay seemed to experience fewer ill effects from hospitalisation and treatment and made a more rapid recovery than the control group who did not have a regular nurse who was trained in effective communication (Skipper & Leonard, 1968). These effects are not only present throughout a hospital stay but can continue long after discharge when the parents and family are faced with issues such as consequent treatment, repeat hospital admissions and appointments that they may be required to administer (Hallstrom et al. 2002).

Young children are viewed as being more vulnerable given their level of cognitive and affective development, their dependency upon adults as well as their lack of understanding surrounding their illness and treatment. The choices and control that they experience are even more limited than those of parents or other adults with the same conditions. Quinton and Rutter (1976) reported that multiple hospitalizations in young children led to school problems for childhood. In some cases however the added stress seemed to strengthen rather than weaken them (Bolig & Weddle, 1988).

Resilient children can therefore often respond differently to hospitalisations than their more vulnerable counterparts (Hägglöf, 1999). During hospitalization resilient children may be viewed as being deviant and may not be provided with the supports necessary to their style of functioning or coping. Some children learn new ways of interacting and acquire a greater sense of control becoming more resilient during illness and hospitalization (Hägglöf, 1999). Resiliency is seen as a characteristic or ability to return rapidly to a previous psychological or physiological state. Resilient children tend to respond quickly and appropriately to major life events such as a chronic illness and hospitalization and can adapt more positively to stressful situations. Hospitals will now allow parents and siblings to have a greater involvement with their children who are hospitalised. Parental involvement can vary from being able to live-in with their child during their stay, to being allowed to be present during any treatment or procedures (Bolig & Weddle, 1988; Hägglöf, 1999). In addition to preventing separation anxiety

parental presence during a hospital stay is assumed to facilitate expression of feelings (Kralik, et al. 2006; Ferguson & Walker, 2014).

There is a noticeable difference between individuals whose parents play a large role in their treatment and care, and who provide support while they are in hospital can provide encouragement and support are able to eliminate unpredictability facilitate emotional regulation (Bolig & Weddle, 1988). Contrasting this, parents who are not or who are unable to be as involved may have children who display greater passivity and defeat. The child will feel more encouraged by the support their caregiver displays. The caregiver can also provide verbal soothing and distracting activities for the child (Bolig & Weddle, 1988).

When a child is hospitalised a parent or caregivers responsibility is taken away from them. This is often distressing for the adult as they lose the power to influence the decisions that are being made (Bolig & Weddle, 1988). Whilst a number of changes have been made regarding the care that families receive it is however important that the health professionals provide enough information about the treatment so that parents are well informed about the condition and treatment plans that are to be implemented (Bolig & Weddle, 1988). Many medical practitioners still fail to recognise the magnitude of emotional problems that are experienced by the parents themselves as well as underestimating the degree of interaction that the parents require and expect (Miles, 2003).

Parents of hospitalized children have rated nursing support as an important influence on their experiences (Miles, 2003). This is not surprising since nurses inform parents of their child's health status and care plan, provide support during times of distress, and educate parents about treatment. The quality of nursing support therefore affects parent's ability to cope with the immediate crisis of a child's illness, the development of their parental roles, and their competence in providing vital care after discharge. Parents have described the vital need for continued communication between nurses and themselves. This includes regular meetings with parents, contact by phone and written notes and encouraging parents to contact the nursing staff at any time (Miles, 2003)

Effects on Development of a Child

Children who have been diagnosed with IBD often experience weight loss or lack of weight gain. This occurs through a decrease in oral intake due to nausea, pain or early satiety (Lemberg & Day, 2015). Thickening of the bowel wall may lead to obstruction and therefore contribute to pain as the food is digested. It is common therefore for children to experience early satiety and/or decrease their oral intake to avoid these painful symptoms, this occurs at both conscious and subconscious levels (Pons, et al, 2009).

Pain associated with eating can lead to poor tolerance of foods and create a fear of unpredictable bowel movements often causing reduced dietary intake (Moeeni & Day, 2011). Malnutrition observed in individuals with IBD most commonly occurs during the acute phase of the condition, however there is also evidence that this occurs during periods of remission (Pons, et al. 2009).

Reduced food intake is of great concern to young individuals with IBD as they require a significantly greater amount of energy during childhood and adolescence for healthy growth and development outcomes (Pons, et al. 2009).

Consequent to poor dietary intake micronutrient deficiencies are also seen. These include calcium, iron, zinc, magnesium, vitamin D, folate and vitamin B₁₂ deficiencies. Reduced food intake in addition to malabsorption and increased intestinal losses of essential nutrients associated with inflammation may therefore lead to persistent nutrition deficiency in childhood CD (Pons, et al. 2009).

Growth problems in children with IBD

Growth retardation has been recognised in the earliest reported descriptions of children with Crohn's disease, and is subsequently described wherever childhood Crohn's disease has been diagnosed (Sanderson, 2014). In addition to weight loss or the inability to gain weight, children also commonly have altered linear growth patterns. Reduced energy intake, increased weight loss and impaired linear growth in pediatric CD are associated

with a low lean body mass index (BMI) and chronic bowel or colon inflammation during disease activity. This can lead to a lower ideal body weight in children with CD and affect the final height achieved (Pons, et al. 2009).

Treatment of bowel inflammation is beneficial to linear growth, demonstrated by the fact that the reported standard height deviation score improves between diagnosis and adult height. Decreased height was noted in up to 88% of a group of 50 children at the time of diagnosis with CD (Moeeni & Day, 2011). However, Alemzadeh et al. (2002) found no significant deficiency in height after they corrected for parental height. Unfortunately new treatment paradigms have not fully eliminated ongoing growth retardation in children ^{even} when lean body mass and fat mass improve (Sanderson, 2014).

Impaired linear growth tends to be more pronounced in males than females. This is generally related to males going through puberty later and for a longer period of time (Moeeni & Day, 2011). Sanderson (2014) describes how UC differs from CD, where children presenting with UC do not appear to have any substantial linear growth complications. It is believed that pubertal delay contributes the slow linear growth, supporting the research findings stated above, it is also thought that CD is a major cause of delayed puberty that is displayed in many of the children diagnosed (Sanderson, 2014).

IBD in children primarily decreases bone formation and linear growth, especially in those affected by Crohn's disease (Dubner, et al., 2009; Sylvester, et al. 2007) In addition, profound and persistent deficits in skeletal muscle mass may also affect bone mass and bone architecture at diagnosis and post-treatment (Sylvester, et al., 2009; Sylvester, et al., 2012).

Children with IBD are at greater risk of low bone mass due to disease and treatment factors. Early identification of children at risk will enable interventions to improve low bone mass. Individuals with IBD are at greater risk of developing disorders such as osteopenia not being as marked as osteoporosis which is when an individual's bones become brittle due to a number of factors, namely a deficiency of calcium or vitamin D (Pons, et al. 2009). Osteopenia is commonly identified in children and adolescents with CD and related directly to the inadequate dietary intake of specific nutrients. It is thought

that mal-absorption of calcium and vitamin D can impact on bone density (Pons, et al. 2009).

Peak bone mass is achieved during early adulthood and is the most important predictor of long-term skeletal health (Sylvester, et al. 2009; Sylvester, et al. 2012). Conditions such as IBD can decrease bone mass and affect bone architecture thereby weakening the skeleton in children. Due to this bony insufficiency IBD may also increase the risk of fractures. Children are usually diagnosed with IBD during the pre- pubertal and pubertal period, a vulnerable time in their physical development. During puberty children normally gain a significant amount of bone mass with elongation and increased bone strength. In addition, children significantly expand skeletal muscle mass which creates larger mechanical forces being critical for normal bone development (Sylvester, et al. 2012)

An additional consequence of nutritional impairment is delayed pubertal development. Given that many children present with IBD, UC or CD in the pre- or peripubertal period; pubertal delay is of significant concern. Failure of disease remission during this crucial stage can have significant consequences such as missed pubertal growth spurt and a reduced final height (Lemberg & Day, 2015).

Co-occurring Anxiety

IBD sufferers will commonly have comorbid anxiety disorders. This co-occurrence is worrying given the link that both conditions have with psychological impairment for individuals (Bannaga & Selinger, 2015; Biedel & Alfano, 2011).

Fear is an emotion that is commonly experienced in childhood. It is described as a common and basic human response to situations or stimuli in which individuals feel that their physical or emotional well-being is threatened (Biedel & Alfano, 2011). Fear is a multidimensional emotion or reaction and consists of the outer expression of behaviour, the inner subjective distress as well as the associated physical or physiological changes that occur (Biedel & Alfano, 2011). The word ‘anxious’ is a part of our everyday

vocabulary with its meaning differing depending on the situation and context that it is being used. In most cases anxiety describes a negative emotional state that individuals usually actively seek to eliminate (Biedel & Alfano, 2011). Fear is used to describe an immediate defence response to a threatening situation with anxiety used to describe apprehension of a future event. Throughout childhood these terms are used interchangeably as well as a visible crossover of physical adverse reactions to both of these emotions (Biedel & Alfano, 2011).

Anxiety disorder (AD) is defined as a feeling of unease, worry, and/or fear that patients are unable to control (Bannaga & Selinger, 2015). AD's can be classified as mild or severe and they will last for a period of 6 months or more. Research shows that AD occurs in IBD patients more often than expected by chance and is more prevalent in CD patients (Bannaga & Selinger, 2015). UC patients also suffer from AD at a much higher rate than the general population as well as patients with other chronic diseases (Bannaga & Selinger, 2015). Anxiety can potentially worsen these disorders leading to greater psychological comorbidity and poorer quality of life. Whilst increased symptoms are present in patients with AD it is unclear whether these symptoms are due to increased bowel inflammation or other symptoms, as the IBD symptoms scoring system cannot differentiate the specific origin of symptoms (Bannaga & Selinger, 2015).

Some studies believe that an IBD female is at greater risk of developing psychiatric disorders while others believe that this view is controversial (Bannaga & Selinger, 2015). A noticeable decrease in quality of life was significantly related with female gender (Bannaga & Selinger, 2015). Female patients are more likely to develop depression. However, other authors have not found a female predominance among anxious patients (Bannaga & Selinger, 2015). A Dutch study of 231 IBD patients suggested that up to 43% had high levels of anxiety, indicative of a psychiatric disorder and that anxiety symptoms and psychiatric complaints in IBD patients are undertreated (Bennebroek Evertsz, et al. 2012). This would indicate that the correlation between symptoms and anxiety levels seems strong (Bannaga & Selinger, 2015).

Evidence has suggested that disorders can interact (Reigada, et al. 2013). For example

anxiety can cause functional impairment and adverse health behaviours, which in turn can contribute indirectly to IBD through mechanisms such as dysregulation of the autonomic or neuroendocrine systems. Co-occurring with these difficulties, the presence of IBD might provoke anxiety disorders therefore creating a cyclical effect (Reigada, et al. 2013). Research also suggests that IBD specific anxiety has been linked to lower quality of life, higher relapse rates as well as an increased number of gastroenterology visits and emergency care. These areas of concern are very rarely assessed or targeted in medical and mental health treatment (Reigada, et al. 2013).

Depressive Symptoms

Psychiatric comorbidity is a common occurrence in patients with IBD with depression and anxiety most likely to be experienced, with a diagnosis of major depression likely to reach 30% over the patient's lifetime and anxiety is likely to feature even more frequently according to Ananthakrishnan, et al. (2013). It is widely reported that individuals with chronic disease experience higher rates of depression compared to healthy controls (Ananthakrishnan, et al., 2013; Boschert, 2006). Depressive symptoms can be classified as any of or a combination of the following; feelings of helplessness or hopelessness, loss of interest in daily activities, sleep changes, anger or irritability and loss of energy or self-loathing (Boschert, 2006). Several risk factors have been identified in relation to depressive symptoms and chronic illness. Individuals who display one or more of these are at higher risk of developing depression or low mood disorder. Individuals who have poor family functioning, poor personal health or low physical functioning are more likely to show signs of depression. Patients with IBD who are being treated with steroids (especially very high doses), as well as having more severe disease symptoms are at much higher risk of developing depression.

Ananthakrishnan and colleagues (2013) suggested that the risk of depression following surgery or IBD related hospitalization increases following these events. This study identified the risk of depression in patients with CD 1, 2 and 5 years after surgery or hospitalisation increased by 6%, 8% and 16% respectively. UC patients had very similar

results with the risk increasing 5%, 7% and 11% respectively. The study also identified a higher incidence of females developing depression, as well as depression being more prevalent in patients who required a stoma (27%) than those who did not have one (15%), and being a younger age when receiving surgery.

Bokemeyer et al (2013) found a high psychosocial burden in IBD patients throughout the development of their disease. This study reported a high incidence of severe depressive symptoms with 14.9% of participants displaying symptoms. The study also highlighted that both CD as well as UC patients were affected by the impairments of psychosocial factors that are associated with IBD. Hardt et al (2010) had similar results with their findings suggesting that there was severe negative psychosocial burden found in patients with diagnosed IBD. Their study included 1083 participants, with 23.6% reporting depressive symptoms, as well as 23.8% reporting relevant anxiety. These results were reported with higher frequencies for CD patients compared to that of UC patients. The control group revealed rates of only 9% for depression and 16% for anxiety.

The conclusive results in the research indicate that the frequencies of clinically relevant anxiety and depressive symptoms are significantly greater in those individuals with diagnosed IBD.

Resilience

Resilience has been described as an individual's ability to bounce back from a time of adversity or crisis and to continue living life with no effect (Fergusson & Walker, 2014; van Loon & Visentin, 2006). There are multiple concepts that allow an individual to display resilience, such as competence, confidence and coherence. These are all important in the development of building resilience in an individual. Resilient individuals are able to adapt or to rebound during a challenging period of time, such as being faced with a chronic illness (Fergusson & Walker, 2014; van Loon & Visentin, 2006). A small amount of research was discovered during the literature search that has focused on building resilience within families and individuals who are experiencing chronic illness (van Loon & Visentin, 2006). Results obtained from qualitative studies conducted by

researchers concluded that resilience was seen in individuals who focused on positive aspects of their lives such as opportunities, influences and their futures, such as goal setting or career prospects (Fergusson & Walker, 2014; van Loon & Visentin, 2006). Resilience can also be displayed in individuals who are resistant to be seen as ‘different’. Many young people did not want to be seen ‘as their illness’ but instead wanted to be seen as themselves. Researchers have discovered strategies that young people and their families demonstrate in order to face challenges in their lives (Fergusson & Walker, 2014; van Loon & Visentin, 2006).

Fatigue

Fatigue is a prevalent and sometimes chronic symptom of IBD and is reported to be one of the most common concerns for IBD patients because of the ability to interfere with daily functioning (Pellino, et al. 2014). It is defined as a lack of energy and feeling of psychological tiredness that is not associated with sadness or weakness (Pellino, et al. 2014). There is a complex interaction between an individual’s biological, psychosocial and behavioural process that are involved in fatigue. Fatigue in IBD is thought to effect individuals similarly to other chronic diseases (Pellino, et al. 2014).

Pellino and colleagues (2014) reported a higher number of CD patients (43%) report severe fatigue compared to that of UC patients (33%) and of the UC patient’s females were more likely than males to develop fatigue. It has also been reported that females tend to follow a more severe disease pathway, having at least one comorbid condition. However, this is controversial as it is difficult to tell if women actually experience more severe fatigue than men or if they have a higher rate of reporting their symptoms and the severity. In addition, CD patients who reported fatigue symptoms had a lower education and were less likely to be employed compared to CD patients who did not report fatigue (Pellino, et al. 2014).

A significant relationship has been identified between disease severity and high levels of fatigue in individuals with IBD. Individuals who experience severe IBD symptoms have increased bowel movements, fever, decreased general well-being and more severe

stomach pain. Individuals who had less severe symptoms of IBD reported fatigue that was comparable to that of the general population (Pellino, et al. 2014).

The respondents identified many factors contributing to IBD-related fatigue and to its severity. These included the severity of IBD, patient's age, anemia, medication, food restrictions and absorption problems, stress and emotions, pain, work and activity, and sleeping problems (Czuber-Cochan, et al. 2014). The active stage of the disease with inflammation and the symptoms that are associated such as diarrhea have been accepted as being key contributors to the presence and the severity of fatigue (Czuber-Cochan, et al. 2014).

Pellino and authors (2014) found that the activity of IBD significantly impacted on perceived fatigue. Interestingly it has been suggested that age played a role in coping mechanisms for IBD and in turn older patients were found to cope better with fatigue than younger patients. Many factors may affect patient-perceived fatigue, with chronic illnesses and conditions being the most important (Pellino, et al. 2014).

The study suggests that whilst age may play a role in levels of reported fatigue, in reality it may be the length of the disease that is of relevance. Patients who have experienced IBD for longer periods of time and have successfully controlled the symptoms may develop more effective coping strategies than younger patients. When younger IBD patients were compared to their same age controls in the study conducted by Opheim et al (2014) levels of fatigue were significantly higher. This study highlights that timely fatigue specific treatments may be needed in these younger patients. Such treatments could be successful in reducing the levels of perceived fatigue so long as the underlying condition (IBD) is controlled (Pellino, et al. 2014). Disease duration and activity have previously been associated with higher fatigue levels (Opheim, et al. 2014). Not surprisingly IBD patients with more active disease were more fatigued than both IBD patients with mild disease and non-IBD patients (Pellino, et al. 2014; Opheim, et al. 2014).

It has been reported that socio-demographic factors are found to be associated with higher fatigue rates in IBD patients and in general populations (Opheim, et al. 2014).

Employment is also associated with a significant number of CD patients reporting that they were unemployed. This could suggest that the fatigue that is reported substantially affects the daily functioning of these individuals. Individuals who have completed higher levels of education and are employed reported lower levels of fatigue. This may be due to more resources and access to services that are able to facilitate this symptom explain better (Opheim, et al. 2014).

Self-Image

Nicholas et al. (2007) highlighted individuals with IBD often compare themselves to their peers, on their appearance as well as their performance in certain areas of their lives. Respondents perceived themselves as thinner, more pale, with some reporting not being as tall, fast or strong as their peers. There were circumstances where peer comments would reinforce these perceptions with comments about their inabilities or their appearances that would contribute to the individual having self-image doubts. In a study done by Griffiths et al. (1999) they discovered that there were differences between the UC and CD cohorts, with a larger number of CD patients having concerns about their height 4:58 (CD:UC) or their body image 9:48 (CD:UC) where 96 is the highest score and 1 is the lowest. As research in this area is sparse these studies were the only two that could be used to substantiate these claims and it is unlikely that they can be generalizable by others (Nicholas, et al. 2007).

Socially

The social impacts of IBD on an individual has been reported by (Nicholas, et al. 2007). Children with IBD are impacted by the number of days that they are absent from school, this greatly impacts the social development in young children (Nicholas et al. 2007). Many individuals find it difficult to participate in activities that 'normal' well children are able to do due to the bouts of illness they experience and not being able to do anything at all during these times. Nicholas et al also highlighted that participants described events such as being bullied because they were not able to join in activities

with other children, or because of the way they looked after taking the required medications. It was also noted within this group that it was often by choice that individuals spent lesser time with their peers due to the fact they were embarrassed by possibly frequently needing to use a public toilet, and the fact that they may accidentally pass wind. These factors alone could impact negatively on the individual and contribute to psychological disorders such as anxiety.

Family Involvement

A number of studies have focused upon family functioning and how this affects the outcome of children with IBD (Gavin & Wysocki, 2006). The results of these studies suggest that the function of the family unit can cause positive or adverse outcomes such as behavioural or emotional functioning, quality of life and the general quality of the disease (Gavin & Wysocki, 2006).

A cohesive family unit was found to have beneficial effects on children diagnosed with IBD, this included families who had a good ability to solve conflict and disagreements (Gavin & Wysocki, 2006). Impairments in a child's quality of life when diagnosed with IBD were reported when the cohesion in a family and their ability to solve conflict and disagreements was compromised. Additionally, it has been reported that families who were over protective of their child and an individual who relied heavily on their family after diagnosis was also said to have a negative impact on the outcomes of the child. This significantly impacted upon the child's ability to become autonomous in the management of IBD once they were at an age where this was appropriate (Gavin & Wysocki, 2006).

Research suggests that families who have a strong support system and open communication can provide protective factors that work to protect against the impact of the disease on psychosocial functioning of young individuals with IBD (Engstrom, 1999). This is supported by the 'Risk and Resistance Model'. This model states that the level of support offered to the child by parents or family adaptations directly relating to the paediatric chronic illness can affect the child's psychological adjustment (Gavin & Wysocki, 2006).

The risk and resistance model also proposes that the adverse effects of risk factors such as diseases like IBD on the children's psychosocial adaptation may decrease if a variety of resistance factors are present in the child's life and environment. Engstrom (1999) examined the use of this model and highlighted some significant results. The model proposes that the adverse effects of risk factors (for example disease or illness) on a child's psychosocial adaptation (mental, social, and school functioning) may be controlled by a variety of resistance factors that can be adapted by parents and families.

Reports have shown too much attention or too little attention can prove to be a risk factor for young individuals with reports of internalizing disorders such as depression and anxiety being common in these individual's (Gavin & Wysocki, 2006). Too much attention surrounding their IBD diagnosis can be viewed as too intrusive or unnecessary, while an individual's family who shows very little attention or no interest may cause more distress during their time of need.

Parental Adjustment

All children are dependent on their parents with this role becoming more compounded when the child has a chronic health condition that requires ongoing care (Kratz, et al. 2009). Parents will take on additional roles such as being carers, medical experts and personal representatives for their child (Kratz et al. 2009). These aspects can result in a parent's social and emotional well-being being negatively impacted. The needs of their child are significant with Kratz (2009) also reporting that families frequently live in a state of exhaustion or heightened emotional states. During this time the parent's own support and social network diminish and feelings of isolation can become prevalent. Parents can fall into one of two categories that have been used to describe how a parent or caregiver copes with their child's diagnosis. Parents or caregivers who are "resolved" integrate information and emotion in a way that promotes their relationship with their child and changes their parental boundaries to include the new caregiving behaviours that are required (Popp, et al. 2014). "Unresolved" parents become stuck in the grief phase of the diagnosis and they tend to adopt behaviours that have the tendency to negatively impact the illness or their relationship with their child (Popp, et al. 2014).

Parents are suddenly faced with new responsibilities and roles when it comes to the day to day care of their child. They are often required to carry out health care routines, make on the spot decisions regarding the medical care and they are required to problem solve medical challenges. They perform these tasks all whilst still maintaining their normal family routines and other demands in different aspects of their lives such as a career (Kratz, et al. 2009).

It is the advanced health care systems that are in place that enable the parents to be critical members of their child's health care team. This enables them to spend less time in hospitals or medical centers and more time in their family's homes. It is the effective partnership between the parents and the health professionals that is vital to ensuring a successful outcome (Kratz, et al. 2009).

There are a number of studies that have focused on the caregiver of family members who have a serious illness and that have reported adverse effects for these individuals (Kratz, et al., 2009; Moller-Leimkuhler & Weisheu, 2011; Popp, et al., 2014)

A number of aspects of their lives are impacted upon such as the carers' quality of life, time spent away from work (leading to financial loss), reduced time available for leisure and social activities, as well as their own adverse health effects. Their health may be affected by increased symptoms and feelings of distress, stigma attached to the illness, and greater use of reported use of medications such as antidepressants and anxiety medication (Moller-Leimkuhler & Weisheu, 2011).

Many studies report conflicting results with regard to concerning levels of anxiety, depression and quality of life (QoL) in parents who have a child with a chronic illness (Clarke, et al., 2009; Picci, et al., 2013; Moller-Leimkuhler & Weisheu, 2011). Similarly, there have been studies that have come to inconclusive outcomes regarding whether a mother or father shows higher psychological distress in the early stages of illness (Picci, et al., 2013; Moller-Leimkuhler & Weisheu, 2011).

One longitudinal study conducted confirmed that there are higher rates of anxiety, depression and insomnia shortly after their child is diagnosed but also that there remains

higher rates of sleep disturbance and depression after many months of the illness being present (Picci, et al., 2013).

Siblings

The effect of IBD on patient's siblings is a topic that is not well researched. Research has instead focused mainly upon the effects of an individual's emotional development, the relationship they have with their sibling and the overall effect that the sibling experiences throughout the journey (McGrath, 2001).

It is unclear whether a close sibling relationship helps mitigate some of the negative effects of exposure to domestic violence or whether children with fewer emotional and behavioural problems are better equipped to form and maintain close sibling relationships.

The sibling relationship creates a powerful experience and unique effects on individual development. When this relationship is compromised by chronic illness and additional family stressors it is likely to take a toll on all the individuals involved.

During the early stages of childhood (up until 6 years of age) it is known that younger children in a family spend just as much time with siblings as they would with a parent (McGrath, 2001). While this is not continued throughout their lifetime, these early interactions impact areas such as personality, opinions, and experiences and in some cases life choices.

McGrath (2001) identified that healthy siblings may be faced with a number of challenges when another sibling is ill. These include feeling a loss of attention and not spending time with parents or their family and commonly feelings of neglect, ignored, isolated and lonely. In some instances, healthy siblings feel guilty because they believe that their sibling became sick because of something that they said or did that caused the illness. These thoughts of the healthy sibling can lead them to believe they were powerful enough for them to make it happen (Murray, 2000).

While it is not consistently reported or shown that healthy siblings have elevated rates of psychopathology, they do have psychosocial needs that mental health professional should recognize and address (McGrath, 2001). It is common for healthy siblings to experience a loss of parental attention and a threatened sense of security within their family environment due to the amount of attention that is required for the sick child (McGrath, 2001). Another common emotion that is displayed by the healthy child is that of resentment. These feelings are displayed by the individual becoming upset that the ill child is receiving all or most of the attention.

As well as the more negative emotions, it is also common for the healthy sibling to show great concern for their ill sibling (McGrath, 2001; Williams, et al., 2009). The lack of understanding of the illness and what is happening at the hospital or medical appointments leads them to wonder if the sibling will ever return home, or even if they will die. This feeling can also be transferred to their parents, with fears that they will also become ill. In the long term, healthy siblings can be seen to display an increase in personal maturation due to the stress of everyday life they are now faced with. They have a greater ability to tolerate anxiety and stressful environments and the ability to regulate these emotions is important in the development of individuals (Williams et al 2009). Another noticeable distinction is the healthy sibling's ability to accept and understand people who display physical or mental difference as they have a greater sensitivity to these people given their own siblings position (Williams, et al. 2009).

Research has highlighted the importance of the medical professionals need to engage a mental health team for the family as well as extended family, and in some cases school staff and relevant community members (McGrath, 2001). The inclusion of the healthy sibling throughout this journey provides them with the needed support and a greater sense of well-being and understanding.

This mental health team can also provide assistance to parents for facilitating them in how to manage both an ill as well as healthy child. The parents should be encouraged to talk to the healthy sibling as well as providing them with their own individual attention to reduce the feelings stated above (McGrath, 2001). It has been found that when healthy

siblings are provided with age appropriate information regarding the illness or disease of the chronically ill child, they are better able to understand, cope, and adjust to the situation (McGrath, 2001).

Treatment and Management

Steroids are the main treatment for stimulating remission in CD and UC patients who are classed as moderate to severe (Shikhare & Kugathansan, 2010). They are generally used in combination with a maintenance therapy in order to achieve the remission that is desired. Many individuals who use steroids for IBD experience a number of adverse short term side effects such as rounding of the face or bloating, mood changes, sleep issues, psychoses, suppressed immune system, which can in turn can lead to more infections (Shikhare & Kugathansan, 2010). Chronic steroid use can also cause growth retardation, osteopenia, permanent skin markings, and cataracts. Given these effects, and where possible steroids should only be used as a short term treatment option (Shikhare & Kugathansan, 2010).

Another treatment and maintenance option for IBD is nutritional therapy, which consists of using a nutritional formula as the primary therapy to induce and maintain remission in CD. The main purpose of this therapy is to improve growth, or to replenish micronutrient deficiency (Shikhare & Kugathansan, 2010). The evidence to support the use of these nutritional supplements is controversial however and is not widely used in a number of countries due to societal expectations and norms. Furthermore, nutritional supplementation has produced varying results and is used more commonly for individuals who cannot maintain weight on the recommended caloric intake for their age (Shikhare & Kugathansan, 2010). Other specific diet changes or modifications have not been well studied.

In many cases patients who have been diagnosed with CD will end up having surgery to manage their disease, in a Canadian study they found that within 15 years of an IBD diagnosis up to 70% of patients will require surgery (Bernstein & Nabalamaba, 2006; Shikhare & Kugathansan, 2010). Whilst medical management remains the first line

treatment for IBD there appears to be relatively similar indications for both UC and CD however the approach and the outcomes differ for both. One benefit in children who do have surgery is that they will have catch up growth spurts (Shikhare & Kugathansan, 2010). The aim of surgery in CD is to remove as little bowel as possible since CD will recur in most patients within 5 years of surgery (Bernstein & Nabalamaba, 2006; Shikhare & Kugathansan, 2010).

Inflammatory bowel disease is a relapsing disease that has a high rate of illness but it has a low mortality rate. Most children with IBD lead active and normal lives with no limitations except during their conditions flare up (Shikhare & Kugathansan, 2010).

Limitations of the literature on families of children who have been hospitalised

This field of research has a number of limitations, which restricts the interpretation of these studies. First is the lack of child focused IBD research. Owing to the number of developmental changes and growth that children are faced with, there is evidence to suggest that children as well as their families experience different issues and challenges from adults who experience the same disorder. Directly related to this, are the challenges that families are faced with, rather than an individual adult experiencing and coping alone. This disorder impacts the whole family unit when an individual is diagnosed at a young age. Previous research does not focus on this family unit, but rather solely the individual with IBD.

Rationale for Current Study

It is clear from the many published studies that have been discussed above, that children who have been diagnosed with IBD as well as their families have profound stress and disruption in their lives. Such experiences can place individual's at risk for adverse psychological effects as well as psychological distress. (Blanchard, et al. 2001).

Research also has a strong focus on adults; however, there is research to suggest that IBD is a medical diagnosis that is becoming commonly diagnosed in children (Zhou, et al. 2012). This younger cohort of people displays differing needs from those of adults who

have the same diagnosis, there will be different challenges that individuals and their families are faced with. What is known however is that the health-related quality of life is reduced for all individuals who have IBS, both school and work as well as social interactions is compromised from having this disorder (Zhou, et al. 2012).

Most IBD research has a strong medical focus highlighting procedures or treatments that are available to individuals with IBD. There are very few studies that have a focus on the psychological burden that chronic illness can affect individuals and their families in patients who have been diagnosed with IBD.

The identification of the barriers and challenges that families are commonly faced with adds to the current research. This study explores the experiences from a younger perspective as well as the family cohort as a whole. With the information and knowledge that is provided it would be possible to improve the care and support that is offered to families in order to reduce the stress's present during this time. Within the literature that was reviewed it was difficult to identify specific research where psychological challenges that families as a whole are faced with were identified.

The following chapter reviews the findings of the current study. The results have been clearly grouped into seven common themes and include subthemes.

Chapter Three: Methodology

This section describes the theoretical framework that underpins the design of the current research. Drawing from this knowledge it has directed me as the researcher through the method that was utilized to conduct this research.

An Overview of Qualitative Research

Qualitative research captures the interaction between the researcher, the participant and the participant's surroundings, the process of data collection and the analysis of the experiences that the participant describes. Qualitative research is a holistic approach which seeks to describe the understanding of people's experiences, conceptions, and behavioural activities (Bogdan & Biklen, 2007).

Due to the scarce published literature derived from subject interviews, qualitative research was the most fitting given the flexible, interpretative and inductive type of approach that it takes. The format of the interviews takes a casual approach with mostly open-ended questions being used, allowing for a more informed and directed answer. The data gathered throughout the interview is done so through audio recording as well as field notes. This allows for the qualitative research to generate in-depth and comprehensive information and be able to revisit the original transcripts and audio.

The sample size of qualitative research is usually small, non-random and theoretical. Qualitative researchers study inherent opinions and want to reflect reality from unique perspectives.

Rationale for Choosing Qualitative Research Approach

The researcher was guided to choose qualitative research approach to the study due to the approach that this methodology took with the participants. This approach added a new dimension of understanding to the current phenomena such as gaining an understanding

of participants' direct experiences and their journey from having a child diagnosed with IBD or understanding groups from an insider's perspective (Wertz, 2005; Wertz, et al., 2011). The researchers aim was to know and understand the experiences and reflections that these families encounter while dealing with the medical system, often numerous medical professionals as well as the aftercare that is required once a diagnosis has been made. Choosing to use this method of research directs the study towards a qualitative design.

Qualitative Research

According to Wertz (2005), the qualitative research design is generally used to answer the phenomena at hand, which are often complex in nature. This is done with the participant describing their unbiased point of view and the researcher trying to understand. Speaking with participants directly we were able to obtain their points of view. For this reason, qualitative research was the most appropriate method for this research. Due the limited amount of literature in this subject area there was no way of knowing what the families would say in relation to what they experienced. Qualitative research seemed the most appropriate for this reason so that the participants could guide the direction of the interview. It was also not practical to hypothesize given the different experiences that families are faced with and different values and areas of importance during their care and treatment.

As a result of this unknown information the analysis was inductive which helped to explore a research field without setting out to verify or invalidate the research question. It also ensured that there were no biases when it came to performing the interviewing with the participants directly.

Qualitative research was therefore the most appropriate for the current research in understanding the lived reality of participants about their thinking regarding the individual experiences that they were faced with.

The lack of research and knowledge that is available surrounding the experiences of families of children with IBD facilitated the research question as well as the research

design and methodological approaches. It was deemed important that the voice of the participants was heard and the information and data that was collected was done from each individual's own voice and story directly relating to their personal experience.

Researchers have suggested that in order to thoroughly investigate people's perceptions and experiences qualitative research methods are able to best explore this (Creswell, 2008; Wertz, 2005; Wertz, 2011). Qualitative research explores a little known phenomenon through the experience of participants and focuses on investigating the naturally occurring events in their natural settings; to many people these may seem like ordinary events (Creswell, 2008; Miles & Huberman, 1994).

Qualitative research is interested in a person's 'real' experience of a particular phenomenon; what they did, what they know, how they think and what they felt (Patton, 2002). The researcher relies on the participant's explanation of their views as well as asking broad open ended questions whilst observing the individual throughout the interview, collecting data that closely reflects these emotions and comments. The data is then systematically analyzed for themes and patterns that recur frequently.

More specifically, phenomenological methodology was utilized. Edmund Husserl is believed to be the founder of phenomenology, with his early definition of this methodology stating that phenomenology is "*a descriptive philosophy of the essences and pure experiences*" (van Manen, 1997, p. 89). Husserl believed that phenomenology aimed to capture a particular experience in its earliest form without interpretation, explanation or theorizing about the phenomena (as cited in van Manen 2014).

The phenomenological point of view to research is to view things the way that they are experienced in the world (van Manen, 1997). To know well and understand the phenomenon that is being explored, individuals have to be in and experience the world first hand. Phenomenology attempts to demonstrate how an individual's own words, concepts and theories can shape and structure the experiences as they live them (van Manen, 1997, Wertz, 2005).

Phenomenology refers to a philosophical method of observing, recording and interpreting the ‘lived experiences’ of certain individuals through detailed descriptions and conversations. This research utilizes phenomenological methodology with an aim to expose, and reveal certain elements of particular situations that are universal to that unique cohort (van Manen, 1997).

Throughout the interview process it is estimated that individuals are able to recall their experiences once certain phenomena present themselves to consciousness, reliving their unique experience and telling their story to the researcher. It is believed that phenomenology is based on the belief that a person cannot reflect on lived experiences whilst they are currently living through that particular experience. In order to reflect, the experience must have already passed or been lived through in order to gain a retrospective perspective (van Manen, 1997, van Manen, 2014). All of the participants selected for the current research have lived through the experience of a child needing hospitalisation for IBD.

Throughout the data collection phase and the results analysis, the phenomenological term ‘the study of essences’ will be closely considered in which the question is asked; what makes something what it is? In an attempt to answer this question researchers, need to uncover and describe the internal meaning structures of lived experience (van Manen, 2014).

Phenomenological methodology best supports this research, as it allows for diversity in responses from individuals. It ensures that each unique family experience is accounted for and gives them the opportunity to tell their own personal story. This particular methodology captures the lived experience of each individual, which is one of the main focuses of this research. Alternatively, there is the ability to also report findings from both individuals and families as a whole in the research methodology and findings (Wertz, 2011).

The Lived Experience

One of the first explanations of the lived experience was developed in 1987 by Wilhelm Dilthey who described the lived experience “*as a reflexive or self-given awareness that inheres in the temporality of consciousness of life as we live it*”. (van Manen, 1997, p. 39). This phenomenon suggests that through language we are able to explain and name the human ‘lived experience’ (van Manen, 1997). In order for individuals to recall their story and to explain their lived experience, the person must have themselves been in the context of a particular event in which another individual is trying to make sense of (van Manen, 1997; Wertz, 2005).

Another explanation of the lived experience has been described by Van Manen who defines this phenomenon “as the intent to directly explore the originality or pre-reflective dimensions of human existence, or, life as we live it” (van Manen, 1997, p. 39). The pre-reflective experience indicates ordinary every day experiences such as eating, walking or driving that we all experience.

Therefore, the lived experience is experience that we all experience before we take a reflective view on it. It is important as a researcher to realise that the direct involvement of the lived experience is always more complex than we as the researcher or reader are able to comprehend, explanations from individuals are always ambiguous and perplexing to interpret.

As a research method, phenomenology is concerned with a more complex interpretation of experience such as the values and impressions of individuals rather than the when, why and how characteristics (van Manen, 1997). Phenomenology tries to show how our words, concepts and theories inevitably shape and give structure to our experiences as we live them (van Manen, 1997). It is a method that has a specific focus on the shared

experiences of individuals. There is an emphasis on the individual's descriptions of experiences and how they experience the phenomenon (Patton, 2002). This technique is utilized to collect a comprehensive understanding of the meaning that is gained from everyday lived experiences (Patton, 2002). It is assumed by phenomenologists that the experiences that individuals encounter can be made sense of and consciously expressed by those who have lived through it (Creswell, 2007).

Data is collected directly from individuals who have the 'lived experience' of the phenomenon being studied. An essence of the experience for all of the participants is gathered and develops a complex description of the different experiences (Creswell, 2007). Researchers are required to develop a comprehensive interpretation of the meaning and experiences that participants have been exposed to.

The researchers are then required to present the phenomenological text in such a way that it makes the reader suddenly 'see' something, in a way that enriches their understanding of the phenomenon that is being explained. There is also an emphasis on the shared experiences of individuals as well as certain qualities that are shared (van Manen, 2014).

It is believed that there are multiple roles for the researcher throughout the data collection process. Lyons and Coyle (2007) describes the researcher's role as having two stages: Firstly, it is important that they put themselves in the shoes of the participants and second it is critical that the researcher asks questions surrounding the words used by the participant while being aware that there is no forthright and/or direct relationship between the descriptions given and what they actually experience (Lyons & Coyle, 2007).

Both an empathic and a critical stance is required while conducting phenomenological research, first it is important to understand the participants point of view and then the researcher needs an outsider's perspective to step back and evaluate the experiences the individuals encountered (Lyons & Coyle, 2007).

Throughout the data collection and data interpretation it is necessary to remain nonjudgmental and open toward the experiences and voices of the participants. Additionally, subjective interpretation of the data requires implementation of the

researcher's beliefs and background knowledge in order to fully understand and to describe the participant's experiences (Lyons & Coyle, 2007).

Accordingly, this study utilizes a qualitative interpretative phenomenological analysis (IPA) framework to examine the shared experiences of its participants. The main focus of the IPA approach is to evaluate the meanings of particular experiences, events and states that the participants have lived through. IPA involves a detailed examination of the participant's experiences of IBD. The personal experiences and perceptions of an event have been used, rather than attempting to produce an objective statement of IBD itself. The process of IPA is dynamic with the researcher playing an active role in the process. The researcher however actively tries to take in the words and experiences of the participants but often this cannot be completely understood (Lyons & Coyle, 2007).

Data was collected from each individual family who had directly experienced caring for and lived with a child with IBD. A composite description of the experience for each individual family was then developed. It was important for the researcher to depict the lived experience as closely as they could while still remaining an objective outsider in the interpretation of meaning and experience of the families (Creswell, 2007). Many researchers have looked at the researcher's role in IPA (Creswell, 2007, Smith & Eatough, 2007; Smith & Osborne, 2007). It is often described as a two-part process and can be broken into a two stage interpretation; participants are trying to make sense of their world while simultaneously the researcher is trying to make sense of the participant's world (Smith & Osborne, 2007). The researcher is required to take both a critical stance as well as an empathic one, simultaneously trying to understand the point of view the participant is explaining and stepping back to evaluate their interpretation of the experience (Smith & Eatough, 2007).

It was necessary the researcher take a nonjudgmental and open minded approach to the voice and perception of the participants, it is however inevitable that throughout the course of the interviews the researcher and the participant co construct the conversation that took place. Additionally, it is important to note that there is not always a straightforward or direct relationship between the story that the participant expresses, and

the experience that they have (Smith & Eatough, 2007).

Strengths and Limitations of the qualitative research design

Validity of Qualitative Research

Due to the nature of qualitative research, a framework of the most critical aspects of the research process has been developed by a number of researchers in order to maintain validity and reliability across research. A number of necessary criteria have been developed which are the standards that are required to be upheld, as well as a number of techniques that should be used, which are described as the methods that are employed to reduce threats to validity (Maxwell, 2005; Mays & Pope, 1995).

Credibility and authenticity are important aspects of qualitative research both playing an important role in the reliability and validity of qualitative research. Credibility has been identified as the leading goal of qualitative research. Assuring credibility refers to the researchers' conscious efforts to report an accurate interpretation of the meaning of the collected data (Mays & Pope, 1995). Researchers ensure that the results accurately reflect the experiences that are described by the participants (Mays & Pope, 1995).

Authenticity relates to how the research portrays the meanings and experiences that the participants who have lived and experienced the phenomenon have described them. Authenticity relies on the researcher reporting the data accurately and with no personal biases that they might have showing in the report (Maxwell, 2005). It is possible that multiple socially constructed and sometimes conflicting concepts may be exposed due to increased attention to authenticity (Maxwell, 2005).

Due to the infinite possibilities of differing interpretations, assumptions and background knowledge that could potentially influence the research process or data collection, close attention is paid to the integrity and credibility of the study process. Systematic research designs are an important aspect to qualitative research in order to demonstrate evidence or critical appraisal (Maxwell, 2005). The need to critically evaluate the data allows the researcher to identify alternative hypotheses and to examine biases. Evidence should be

provided to ensure researchers interpretations are a true representation of the population and removes distortion or speculation (Maxwell, 2005).

Integrity is a highly important aspect of critical reflection and analysis during the interpretation of the results. Interpretive research suggests that there is always subjectivity and that the researcher is seen as a person who will interpret the data uniquely (Mays & Pope, 1995). Therefore, integrity must be demonstrated in the process to ensure the interpretation is valid and supported within the data (Mays & Pope, 1995).

In order to ensure integrity is held, researchers are required to be self-critical and seek truth at each phase of data collection (Johnson, 1999). Integrity and criticality are represented through reclusive and repetitive checks of interpretations (Ambert, et al. 1995). Validity threats of investigator bias, inattention to discrepant data, or not considering alternative understandings (reflective of Maxwell's conceptualization of theoretical validity) are addressed. Ideally, knowledge claims made by investigators should demonstrate integrity and criticality through a responsible and substantiated scientific process (Smith, 1990).

Criticisms of Qualitative Research

It is a common perception that qualitative research is an anecdote of the researcher's perception of a particular phenomenon, and that it is strongly biased towards the researcher's beliefs or understandings of what they are researching. The issues of qualitative research cannot be addressed by a single phenomenon or constant method given the vast array of approaches that can be used. It can however be judged through the various perspectives such as, 'credibility', 'confirmability', 'ethics' and 'dependability'.

Qualitative research is largely flexible. Researchers are dependent on the subjective views of the participants which will shape the frame work and at times the whole data collection of the phenomenon in question (Creswell, 1994). A result of this is that the creation and the recreation of the research and multiple realities may be numerous and vary greatly due to the differing and unpredictable field situations. With study replication being a concern it has been argued that qualitative research lacks the ability to be

reproduced, in that, the research is personal to the researcher so it cannot be guaranteed that another researcher could replicate what has already been concluded.

The generalizability of the research can also be questionable with a large number of detailed information and data being obtained about a relatively small number of phenomena.

In addition to the aforementioned issues, ethical questions are also important attributes to evaluate the quality of research. Researchers are often directly involved with the phenomenon and individuals affected. This has the potential to affect the outcomes of the research as values and emotions of the participants are likely to vary greatly (Guillemin & Gillam 2004). Similarly, researchers could be faced with consequences in fieldwork that were not predetermined and unable to be solved by the guidelines that are provided by the ethical committee involved. If this was to occur, it would be possible to conclude that the ethical consideration may be unlikely to substantiate the quality of the research (Guillemin & Gillam 2004).

Furthermore, other concerns or additional issues, such as “triangulation” and “crystallization,” choosing appropriate data collection methods, types of data analysis, and processes of writing qualitative notes may be considered to be significant aspects of judging quality in qualitative research (Guillemin & Gillam 2004).

Data Analysis

In qualitative research, there is no single and simple way to analyze the collected data. It requires intellectual precision and a comprehensive analysis. Bogdan and Biklen (2007), describe the data analysis as a procedure of searching the transcripts systematically and arranging the notes and other materials that the researcher accumulates such as voice recordings in a way that enable the researcher to come up with findings. Additionally, the word ‘analysis’ is defined as the process of collecting and gathering data. From this it is then necessary to break the data into manageable units, code them and finally search for patterns within the data. Following this process, the researcher undertook strict systematic rigor during the data analysis.

Data analysis is the process of data reduction (Grbich, 2007). In the current study, preliminary analysis occurred at each stage of data collection. By continuously asking “what is the experience of this parent and the family having a child with IBD?”; “is it impacting on parental stress?” and “does the ongoing care impact the family?” a picture emerged of what is like to live with a child who has IBD and who has been in hospital.

One of the most common dilemmas of collecting phenomenological data is that the participant knows no more than they are telling us. And the researcher does not know what any of it means. It is during that moment in the data collection that it is vital the researcher refrains from placing any comparative values on any aspect of the participant’s narrative or perspective.

A technique called horizontalisation refers to the need to consider each part of the content of their narrative, and the process to be of equal importance. Furthermore, the ability to identify parts of the story and the experience will inevitably be limited by the researchers own life experience. Horizontalisation was utilized, with significant points or phrases in the qualitative data (which provided insight and understanding of each participant’s experience) colour-coded with highlighter pens and noted on a summary sheet attached to the interview form (Creswell, 2007; Moustakas, 1994). Also noted were contextual factors which may have influenced the contact, results of questionnaire and scale forms, and any factors which needed follow-up. In this way, understanding of the research area developed as data collection progressed.

Descriptive analysis aims to describe a phenomenon; the lived experience as described by individuals is used to develop a universal description of their experiences (Wojnar & Swanson, 2007).

Four steps are commonly used in the analysis of phenomenological data; these include bracketing, analyzing, intuiting and describing.

Bracketing

Researchers attempt to achieve a neutral perspective of the phenomena through putting aside prior knowledge or understanding that they might have of the phenomenon that is

being investigated. This can be achieved through interactions with individuals who are directly involved or have personal experience with the phenomena or through acting with a sense of caution of their own personal bias that might impact the data collection (Wojnar & Swanson, 2007).

Analysing

Thorough analysis of the collected data is then required. A five step guide has been developed for researchers to follow to achieve this:

1. Reading and rereading the descriptions that participants have provided during interviews to gain an understanding of their feelings and experiences.
 2. Extract significant statements that are directly related to the phenomenon.
 3. Formulating meanings for these significant statements.
 4. Categorize themes that are common with all participants. Original copies of the transcript must be referred to, to ensure validation and to confirm consistency of the conclusions when compared to the participant's original stories and statements.
 5. Integrating the findings into description of the phenomenon being studied.
- (Edward & Welch, 2011).

This five step analysis has been utilized in this study so that the themes in the interviews can be clearly identified. The ability to collate and present the information in a neat and concise way is easily achieved using this method. It also enables the researcher clear guidelines to follow so that they are able to analyse the data themselves (Wojnar & Swanson, 2007).

Intuiting

Throughout data collection the researcher will become increasingly familiar with experiences that have been had by participants; this allows them to develop an innate sense of that it might be like to experience the particular phenomenon, to put themselves in their shoes. This intuition is developed through listening, reflection and an effort to try to understand what the individuals experienced (Wojnar & Swanson, 2007).

Describing

A description of the essential structures of the phenomenon that is being investigated is presented last. The description provides a ‘story’ of the experiences that individuals have endured and provide insight into what it is like to live through the phenomenon of focus (Wojnar & Swanson, 2007).

Chapter Four: Method

This chapter introduces the participants and outlines the methods and the ethical considerations used in the study. This is then followed by the reality of the methods that took place during the implementation of the research.

Participants

This section presents a brief summary of each family, specifically outlining the family structure, history of the diagnosis, illness and hospitalisation that the child has encountered. As well as this a brief overview of the family is given as well as their approach to the illness.

Participant One

The Participant One was the mother of a family that lived approximately 40 minutes from the nearest local hospital. The family consisted of Mother and Father, the diagnosed daughter who was nearly five years old, and two older brothers. The mother of this family had to give up working when their daughter became really unwell, the father works full time. The participant's daughter had been diagnosed with IBD when she was just over two years old, she had not been 'right' since birth, and was a very small petite baby, as her Mother explained to me. Her diagnosis was very fast, within a couple of weeks of finding blood in her stool she had had extensive testing and gained a diagnosis of Chron's.

Not long before the diagnosis of their daughter, the middle son was diagnosed with celiac disease, so they were only just starting to adjust to that diagnosis when their daughter was discovered to have a lifelong chronic illness. This family's daughter has been admitted to hospital three times and been in the day ward once, for Chron's related illness. The mother stated that compared to some families they have been very lucky with these

admissions, and while it doesn't mean she will be like this forever they don't know what the future holds for her.

Participant Two

Participant Two and her family lived centrally; their family was made up of Mum and Dad, as well as their 9-year-old daughter who has the diagnosis of IBD, specifically UC. There are also two sons, one older and one younger than the diagnosed daughter. The mother of this family gave up work when she was spending a lot of time off work with her sick daughter, her husband works fulltime. It was a relief for this family getting a diagnosis for their daughter, this meant that they were able to begin to understand why she was experiencing the symptoms she had. Their daughter spent 10 days in hospital over the Christmas break one year, she didn't improve in the way the doctors were expecting and didn't respond to the medications that they were administering. The mother of this family stayed in the hospital with her daughter for the entirety of her hospital admission, and stated if "*she wasn't there she wasn't sure what would have happened*" because she did a lot of the care such as the toileting for her daughter.

The family of this young girl have done a lot of their own research about Chron's disease, they have since started her on a gluten and lactose free diet and they have been taking their daughter for alternative therapy which has a focus on the "*different layers in a human body*".

Participant Three

Participant Three lived in a suburb about 10 minutes away from the central city; the family included the mother and father, their youngest daughter who had been diagnosed with Chron's disease, as well as an older sister who lived at home. There were also older half siblings who did not live at the family home anymore. Their daughter was diagnosed with Chron's disease when she was almost 13 years old; she was 14 at the time of the interview. This family initially was under the care of a private practitioner; they were referred there by their doctor. They believed they were getting the best available care, because it is often thought that private specialists are more beneficial. The mother shared

that they did not have the good experience they expected in the private system, it was suggested to them by a family friend that they get their daughter into the public system. They did and this resulted in continued improvement. The mother talked about having a sense of freedom, given their children's ages, before the diagnosis. After the diagnosis they had some of that freedom removed again. The daughter in this family was admitted to hospital once because of the intolerable pain that she was in. As well as this she has had a bowel resection which resulted in positive outcomes for her. She has been well since this surgery.

Participant Four

Participant Four and her family lived about 30 minutes from a small town; this family was made up of four members, the Mother and Father, and the son who had a diagnosis of Chron's and a younger sister. This family was living in Australia at the time of their son's diagnosis; they lived in a small rural town. The son had been diagnosed with Chron's when he was just 13 months old, it was a relatively long process for this family because he was so young, and there had only been 3 confirmed cases at this time of IBD in a child so young in Australasia. The specialists in Australia did a vast number of tests on him and could not find a diagnosis, it wasn't until a planned trip to South Africa when the participant's son became chronically ill on the flight, and ended up in hospital for 10 days. The specialist team in South Africa made the diagnosis, which was reported to the Australian doctors by the mother. These results were initially ignored but an array of further testing, eventually led to agreement on the original diagnosis of Chron's disease. After about two and a half years the family decided they would move to New Zealand, subsequently coming under the care of the Professor specialising in IBD. They received treatment at their nearest hospital, a couple of hours drive from their family home. The mother of this family could not work during this time, and the father worked full time. When they first moved back to New Zealand the father would work one week at home and one week back in Australia.

Earlier this year the parents in this family were asked to talk about their experience at Camp Purple as guest speakers. Camp Purple is a countrywide event that is held over one

weekend each year where children and adolescents as well as their families can connect with people their own age going through a similar IBD journey. People attending their talk expressed surprise that they were so positive given everything they had been through and faced. They responded mentioning their realisation, in the hospital, that there are much worse things around than Chron's disease. This comment captures the positive outlook and approach this family had on their situation.

The participant's son has had his bowel removed in the last couple of years. He was 12 at the time of the interview and is currently still on one medication. The operation has allowed him to live normally since then. The son in this family had been hospitalised many times, especially when he was very young. They spent much of their time during his early years of chronic illness back and forward between their family home and the hospital for periods of time of up to a couple of months.

Participant Characteristics

Participants were mothers from four families who were purposefully selected to the study because they had a child who had been admitted to hospital symptoms of IBD.

Demographic information was not collected from the participants, but the researcher was able to collate that all four families had both biological parents and siblings living in the family homes. In two cases the mothers have had to give up working full time, with the other mothers being able to work part time to meet the needs of their child. All of the fathers had professional full time work.

The children's ages ranged from five to 16 years with a median age of 9.75 years. The ages of the children all met criteria of being 16 years or younger. Three of the families had children under 10 years old and had all of these had an early diagnosis of the condition i.e. 13 months, 2 years and 5 years old. The family with the oldest child in the study also had the latest diagnosis, with her being diagnosed at 14 years of age. In all cases the siblings in the family were within 18 months to two years' age difference of the diagnosed child.

Of the participant families recruited three of the diagnosed children were female, and one male.

Two of the families involved had moved to the main center where the research was conducted from other cities and had no immediate family living in the same town as them, and in one case they had moved from the United Kingdom before having children, their family remained overseas. All participants were New Zealand Europeans, as is consistent with current statistical evidence on the demographics of individuals with IBD.

Recruitment

The initial recruitment phase consisted of the researcher contacting the medical specialist for IBD who was able to provide a list of patients in his care and their contact details. It was necessary for the researcher to visit the local tertiary hospital in order to gain access to this list and to select the potential participants. Initially all participants who were 16 years or younger were selected given the small number of children who met the criteria for an IBD diagnosis and hospitalization.

The potential sample group for this study was all families who had children that had been previously diagnosed with IBD, and who had spent time in hospital for this condition. The pediatric team at the regional district health board (DHB) was able to provide a list of 26 potential families for the author to contact.

Given the above inclusion criteria, some families had to be excluded from the study. These include families who have children that are over the age of 16 years old, and families where the child has a diagnosis of IBD but has not required hospitalization.

Initial recruitment began with a phone call to potential families to ensure that they were willing to participate in the study and to provide initial information before the consent and full information forms were sent to them. Initially it was intended that the pediatric nurse at the hospital would contact the participants to explain the research to them, and then in turn the participants would contact the researcher directly if they were interested in participating.

Once each mother had agreed to participate in the study a hard copy of the information was posted by mail to the participants. The researcher waited for contact to be made by the individual families who would attend the interview to make a time and select a location that was suitable for them.

In all cases the participants chose the family home for the interview to take place. The consent form was completed and returned to the researcher during the interview process.

Participation in the study was by way of purposeful selection. Families who were in the care of the children's pediatric team at the local tertiary hospital were intentionally selected into the study if they had recent hospital admissions and the child was aged 16 or under. This was to ensure that their stories were recent and could provide the meaningful information needed to understand the real-world experience of having a child with IBD admitted to hospital and the ongoing care required. Notwithstanding purposeful selection, all parties participated in the study of their own free agency.

Furthermore, the Children's pediatric team at regional (DHB) was chosen because of the accessibility for the researcher to make contact with families and health professionals who work closely with these families.

Interviews

Qualitative methods in the form of face-to-face semi-structured interviews were initially planned to be conducted with parents, caregivers and/or extended family of children who had been previously diagnosed with IBD and who had spent time in hospital for the disorder. The interviews were estimated to take between 60-90-minutes at a location of the family's choice. Only one meeting was thought to be required in order to gather the necessary data. The purpose of interviews was to ensure that participants were given a chance to voice their experience and to further explore the insight and knowledge that the individuals have of the particular experience. An interview schedule was derived from current literature but participants were also given the opportunity to lead the interview and to talk about what they felt were the most important experiences. Open-ended questions were used to allow participants the opportunity to describe and explain their

personal experience.

Interviews were planned to be held in mutually agreeable locations such as local cafes, the family's home or other public areas to ensure ease and comfort of the participants throughout the interview process. The participant's social situations were considered by offering them a situation that suited them. It was possible that they had other family members who would be attending the interviews so by holding them in a location such as a park or the family home it meant that the children could be entertained. By choice an interview at a café was the least preferred option as they do not offer much privacy and are often noisy, however, this still provided a place where a parent could leave their home but still be in a familiar comfortable place. Conducting face-to-face interviews allowed the non-verbal messages of participants such as emotions that were clearly visible to be observed throughout the interview significantly increasing the validity of the interview and the data collected. All interviews were conducted by the researcher who recorded the interviews with an audio tape recorder as well as hand-written notes of the participant's responses.

Transcripts

In the first stage of data analysis, the researcher transcribed the participant's interviews. These were translated to avoid participants' unnecessary lengthy, halted and paused conversations (Bogdan & Biklen, 2007). The researcher recorded all the interviews digitally, (audio recorded) which helped with ease and speed of the review, as well as the ability to accurately transcribe and to reflect on emerging the themes found during the interviews. Bogdan and Biklen (2007) argued that the crucial part of data analysis is creating a list of coding categories after data collection, and due to do this they advised researcher to carry out the following:

To search for the patterns and consistencies within the collected data as well as identify themes that has been collected. It is recommended that the researcher write key words and phrases that represent these topics and patterns that have been identified. These words and phrases are used as coding categories. Developing a list of these coded themes

after the data has been collected allows the researcher to easily sort them, which is a crucial step in the data analysis process.

It was important for the researcher to read the transcripts several times to familiarize themselves with the data. A coding system was used within the transcripts so that the themes and sub-themes were easy to explore. The codes used were a numbering system based on the order of the interviews, (e.g. 1 for the first interview, 2 for the second).

Themes were then identified using colour while analysing the data. For example coding effects on a child's temperament = blue, financial = green and so on. This process helped to organise the data into probable themes or categories on computer files so that they could easily be traced and similar themes were grouped in the same location.

Participation

In total a list of 26 children and their families were supplied as potential participants for this study. Seven families were initially contacted to be part of this study with all agreeing to participate. In total four families were interviewed for this study, the researcher had difficulty contacting one family, and one family was unable to complete the interview at the arranged time.

Ethical Considerations

Throughout the planning and implementation of this study, awareness has been maintained that families who have experienced their child's hospitalization and ongoing care might experience high levels of distress. Accordingly, this study has been designed to gather the information necessary to address the research question with minimal imposition to participants.

Ethics approval for this research was obtained by The University of Canterbury's Educational Research Human Ethics Committee (See Appendix C). Throughout the planning stages of this research awareness of the distress that families may have endured through the journey of their child being diagnosed with IBD and through hospitalisation and ongoing care was taken into consideration. The phenomenological research design

implemented for this research meant that the interviews were non-invasive with the participants free to discuss areas that they viewed as important, therefore providing minimal distress on the participant. Procedures were in place to ensure that participants had the correct support and care if they were to become significantly distressed.

All participants received written and verbal information regarding the study and consent forms prior to the study commencing. Written information containing details about the study was given to families detailing the purpose of the study and what was required of them. Participants were given the opportunity to withdraw from the research up until the time of data analysis without consequence. Their consent also included permission to be audio recorded during the interviews to ensure the reliability of the data that was being collected (See appendix B).

All participants were guaranteed confidentiality and anonymity throughout the course of the research. Consequently, number-codes have been used to identify the participants. No personal information that can identify individuals has been used, such as their location. Participants have been informed of where the information will be stored and for the length of time it is required to be kept. They have also been offered a copy of the written report once completed.

At no stage has intentional deceit been involved nor information purposefully withheld from participants. Upon completion of the study, participants were sincerely thanked for their valuable contribution and provided with supermarket vouchers in acknowledgement of their participation.

Ethical Consent

Due to the facilitation required in gaining participants from patients under the care of the Children's paediatric team at the local DHB, additional site consent and approval from their ethics committee was required.

Additionally, Maori Consultation was needed to ensure that cultural consideration had been met throughout the planning of the study. Due to the nature of the present study, the demographic was small and were intimately known by the staff involved with recruitment so it was known before the planning stages that there were only New Zealand European participants. However, cultural consideration had been considered and was discussed throughout the Maori Consultation process.

Due to the nature of the consent and the unfamiliarity of the researcher with the DHB system there was a considerable delay with communication as well as getting the consent approved. This in turn delayed the recruitment process; the effect of this was that the researcher was required to place a hold on the study, as information was not available until the consent was approved.

Method: The Reality

During the recruitment period, all families who met the above criteria were contacted by the researcher who informed them of the study. Families were given a brief introduction to the researcher, as well as the study that was to be conducted, after this time the individual was advised to ask any questions about the study and told they could talk to subsequent family members before making a decision on participation. Families were advised their participation was completely voluntary and would not impact on their treatment or care that was being provided at the hospital or in the community.

During the planning stages of this research it was thought that the contact would be made by the pediatric nurses directly with the families to inform them of the research. In reality the nurses at the hospital were not in a position to contact the participants individually, due to their busy schedules and this would have taken valuable time out of their working day. During the phone calls I made sure that I was aware of my ethical responsibilities and ensured that the participants did not feel pressure in participating in this study. Given this, it was overwhelming to know how interested they were in participating and hoping to make a difference to others in the future.

The researcher was then required to phone the participants herself, with the participants having no prior knowledge to the research at all. During the phone calls with the participants the researcher was able to gauge if they were interested in participating or not. Out of all the potential participants that the researcher was able to reach and physically speak too, not just leaving a message, all participants responded that they were interested in participating.

After the initial contact was made families were given some time to think about their participation. Those parents who had indicated that it was a possibility and had asked for more information were sent the information sheet and the consent forms. Ten days after initial contact the researcher made a follow up phone call or text message with potential families, it was then if the families had agreed to participate that a time, date and location was discussed and agreed upon. Verbal confirmation over the phone to participate in the study was what the researcher initially used as consent and the individual was deemed a participant in the study.

In all cases participants suggested that they would prefer the interviews to be conducted at their family's home, three families of which lived in a major city and the surrounding towns, and one family in a smaller town.

Data Collection: The Reality

Upon completion of the family consent form, parents were invited to continue with the initial interview at a time and location of their choice. In the case of all four mothers agreed to meeting at their family home. Qualitative data in the form of semi-structured interviews were collected throughout the duration of the study. In all cases face-to-face interviews were held with the participant mothers, who played important roles in the care of the child with IBD. The duration of each interview was approximately one hour.

Chapter Five: Results

The aim of the study was to explore the experiences families have throughout the diagnosis and care of a child with IBD. The primary objective for this was to explore the lived experience, and the personal perception that each individual family had encountered. The researcher analysed the data that was gathered throughout the semi-structured interviews using the methods that were previously described. From the data it was clear there were six common themes throughout the participants. A number of subthemes were identified within the six main themes.

Analysis

Consistent with the IPA method (Smith & Osborn, 2003), there was no predetermined hypothesis for this research. Rather, this researcher aimed to explore the perception that families have of their experience and journey with a child with IBD, the researcher aimed to gather information about the medical care received, as well as relationships, and psychological distress or resilience that the individuals displayed. By utilizing the phenomenological approach this allowed the participant to speak freely and openly about what they deemed to be the most significant factors in their own personal journey.

In an article written by Smith and Osborn (2003) it is specifically stated that IPA methodology is not rigid, but rather it can be used as a guideline in which flexibility can be utilized, it gives the individual researcher the ability to adapt it to fit their specific research aims. The current study is based on the guidelines for analysis as described by Smith and Osborn (2003).

The IPA guidelines require the researcher to become fully immersed in each transcript; the analysis requires the researcher to read and re-read the transcript several times. During the multiple readings of each account and transcript, there often comes new discovery or fresh insight. It is during this close interaction between the researcher and

the text that the researcher is required to draw upon their resources to interpret and to understand the story that is emerging (Brocki & Weardon, 2006). During this process a simultaneous interpretation occurs, the participants are recalling their story and trying to make sense of their journey, as well as the researcher endeavouring to understand the lived experience that the participant is explaining (Smith & Osborn, 2003).

The analysis is subject to the researcher's own interpretations, perceptions and biases of the data. Therefore, IPA can be described as a dynamic process, in that both the active interpretation of the researcher as well as the individual's personal perception is involved in the analysis (Smith & Osborn, 2003). Every effort was made by the researcher to avoid or reduce the bias of personal knowledge in the interpretation and analysis of the data gathered.

Each transcript was read several times by the researcher, initial reactions, comments and thoughts that were provoked during these initial readings were highlighted or a sticky note was attached to the transcripts. From the initial findings, these were then transformed and blended into developing themes or phrases/comments and noted on a separate piece of paper using the coordinating colour from the first phase of analysis. This detailed analysis was replicated on each of the four participant's transcripts; from this a set of subthemes was produced.

From the produced data, a table was created of all participants and their subthemes. Any common themes that were relevant to two or more participants were included in the next phase of analysis. Subthemes were grouped appropriately, and during this time the researcher consistently referred back to the original transcripts to ensure that the interpretation of the data had not deviated from the original story.

The final stage of analysis was completed by giving each cluster or theme a name appropriately representing the subthemes associated with each theme. From this a table of themes and subthemes was produced.

Researcher Bias

It is virtually impossible as a researcher to completely avoid bias in the analysis. Many researchers' select a topic to study based on some prior knowledge or interest in the focus topic or similar related topics (Smith & Osborn, 2003). However, the researcher comes from a neutral approach whereby they are not a health practitioner and they do not have any prior knowledge about IBD, only the information that was gained through the literature review. Therefore, no expert knowledge was previously had of IBD itself and all the information the researcher gathered was through her own research, and information was also gathered from the interviews. It is seen as the responsibility of the analyst to minimize as much bias that could be imposed on the analysis of the data, as they are able too. Throughout the course of this research, every effort was made to reduce bias, including during the analysis phase where the researcher remained consistently conscious of any possible bias due to prior knowledge, personal or academic experience and any learning that occurred throughout the journey. The potential for bias was also alleviated by ensuring that any of the themes that were identified were relatable to the transcripts of the participants and the reliability checks that were discussed previously were utilized.

Due to the researchers intention to become a psychologist and to work closely with children and their families this may have influenced the lens through which the stories were heard and the data was interpreted. Because of the intention to work in the field of child and family psychology, I was mindful of the importance of active listening and observing body language of the participants. I remained open to them sharing their stories and leading the interviews rather than directing the interviews, therefore, reducing any researcher bias.

Results

Each of the participants, without prompting, described a number of common occurrences

throughout their journey. Because this study focuses on the experiences that families have with a child with IBD who has spent time in hospital, and because exploring the type of medical treatment and care that they received was not an aim of this study, the results presented reflect each participant's psychological phenomena, and that of their family. A benefit of recruiting participants who have a variety of geographic locations, age of child and family make up is that there will ideally be different challenges and difficulties that each family is faced with, providing retrospective insight into additional care or support that could be provided to families in similar situations or on similar journeys. This chapter moves in and out of the participant's voice, the literature and the researcher's observation, as well as gathering information from all of these sources to come to conclusions that perhaps did not have a clear and concise answer. This perspective was taken in order to give the reader a fuller picture and understanding of the results that were gathered.

List of Themes

1. Effect on the child's characteristics

Anxiety

Sadness

Anger

Resilience

2. Guilt

3. School

Difficulty forming and maintaining relationships

Academic Difficulty

4. Emotional Toll on Family

5. Divided Family

6. Financial Stressors

7. Psychological Support

Effect on the child's characteristics. A key theme that emerged from the analysis was that of the noticeable change in the child's temperament throughout their journey with IBD. The participants noted a variety of behaviours and emotions that were prevalent among all of the participant's children. The emotions sadness and anger are used interchangeably throughout the research given the difficulty children have with regulating these emotions. The researcher has explored these emotions separately given how different these behaviours are within the mothers' stories. This finding was consistent with previous research on the effects of chronic illness on children, especially those who have been hospitalized or who are regularly exposed to painful or uncomfortable procedures. (Bolig & Weddle, 1988; Skipper & Leonard, 1968). An interesting observation that the researcher had throughout this study was the positive outlook that the mothers had about their child's illness, and the fact that they had very few negative experiences throughout their hospital stays. This could have had positive influences on the child. Additionally, there were some body cues that were obvious to the researcher during the descriptions of the observed changes in their child. Many participants would change their eye gaze and hang their head lower when talking about the more negative impacts that their child has experienced. This body language, displayed by the participant mirrored the story that was being shared by the mother. Conversely throughout the positive explanations of resilience they displayed posture of someone who was proud of their child, they spoke louder, with more confidence and sat taller in their seat. Listed under clear headings below are the individual subthemes that were identified throughout the analysis.

Anxiety. The subtheme of anxiety, was evident in the accounts of most participants, one participant describes the shock and the surprise at having to deal with their child's anxiety. Throughout some interviews, the researcher interpreted that some of the

behaviours that were being described were directly correlated to anxiety. The emergence of this theme is consistent with previous findings that IBD and anxiety disorders act in a cyclical system (Reigada, et al. 2013). Anxiety or fear as it can commonly be perceived as in children (Biedel & Alfano, 2011) can occur when the individual feels that their physical or emotional well-being is threatened, or they feel apprehension towards an event in the future. For these participant's children who had IBD these feelings were commonly felt in relation to medical treatment that they were going to receive such as painful procedures, or socializing with peers. Such experiences in the past might have negatively reinforced these feelings of fear and anxiety in the children, further enhancing the anxiety that they feel and experience in these situations. Here participant two talks about the surprise of dealing with anxiety as well as IBD;

“It was a huge shock to us as a family, you are diagnosed with the disease and you do a lot of finding out for yourselves, there is no information anywhere on the mental impact, we had no idea of the panic attacks or anxiety that we would have to deal with”.

Research shows us that individuals who have a chronic illness such as IBD are at higher risk of developing an anxiety disorder, this can be due to a number of things namely, social situations and being worried about the location of a bathroom and then consequently needing to spend a lot of time in there (Bannaga & Selinger, 2015; Biedel & Alfano, 2011). Participant two reflects on her child's socialization and indirectly the confidence that she lacks due to her illness;

“She doesn't socialize as much as she used to, and she gets anxiety about going to new places”.

All participants described the anxiety that their children had developed around social situations, this could be due to a number of reasons, the first described below by participant two;

“Anxiety has been the biggest change in her personality, where she once would just go and do things she now really has to take a step back and think about if she is able to go out and do stuff. A lot of adjusting always thinking about having access to a toilet.”

Participant one talks about a trait her young child has developed that is seen as a comforting technique, many young children develop this habit to feel more secure, less anxious and use it as a comfort when they are in situations that provoke anxiety:

“She has a wheat bag that goes everywhere with her, it’s like a reassurance and she can’t be without it. When she starts school I don’t know what will happen because she won’t be able to have it. She has a teddy that is a transitional object.”

Two participants talk about anxiety surrounding the medical treatments that their child required, specifically needles from the blood tests that are performed on a regular basis. One parent describes the resistance that was noticed once the anxiety became apparent as being the one thing her child could control about the illness, her saying ‘no’ allowed her to decide when it could happen and how it was to be performed. Complementing previous research on anxiety and medical procedures, it is clear from this participant’s child that her anxiety has developed out of knowing what is coming and that it will be painful or unpleasant. Participant Two talks about one experience of her child being hospitalized;

“She got really sick over Christmas, we went away on holiday and when we came back she went into hospital for 10 days. It was quite traumatic because she was so dehydrated she was hooked up to an IV line and she became really anxious about the needles.”

Participant One talks about the experience of her young daughter and ways that the medical staff tried to overcome the anxiety that she was obviously displaying towards needles and painful medical procedures;

“The most traumatic thing has been the blood tests, it was very traumatic. We were offered play therapy, but it didn’t work because she was quite switched on. She knew what was going on and she knew no matter how many times she was shown or got to play with the equipment it was still going to hurt. It was good but it was not helpful, it really depends on the child I think.”

As the literature suggests the participants in this study did appear to display a significant amount of anxiety relating directly to symptoms or medical treatment of their illness. In

many cases it could also be concluded that as Biedel & Alfano, (2011) established in their study is that the children could have been demonstrating fear as a response to certain stimuli. From the parent's descriptions behaviours of avoidance were prevalent, demonstrating the immediate defence response to a stimuli or event that the child is aware of, and the individual is actively trying to eliminate this (Biedel & Alfano, 2011). As Biedel & Alfano, (2011) talk about the terms, "fear" and "anxiety" are interchanged throughout childhood. The behaviours mentioned above have been described by the researcher as "anxiety" throughout this subtheme, given that in many of the cases the children are also apprehensive about future events such as medical procedures, taking medication and socialising with peers.

Sadness. For most of the participants they described a sense of sadness in their child that had developed throughout their illness. Much of the sadness came from not being able or well enough to join siblings or friends doing fun activities, through feeling so unwell they were not able to move off the couch during periods of chronic pain and illness, and a sadness that they wanted to be well and not sick anymore.

The sadness was especially evident during bouts of chronic illness, and would be apparent visually in withdrawal from all areas of life including themselves. The participants were able to notice this emotional difference even in their very young child;

"We can see changes even though she is so young. It has changed her emotionally; she is not as happy or outgoing anymore. I would imagine that it's quite common for children with IBD to develop depression later in life" [Participant One].

Participant two commented that her child is *"a lot more sad"* since she has had IBD, she also commented on whether the *"medications can cause a change of hormones in their body"*. Studies have shown that individuals who are treated for their illness with steroids, and especially high doses do have higher rates of depression so it is possible that the individuals in this study have been affected by them in this way, however, due to the nature of the current research it is not possible to show what the exact effects of the child's sadness is.

Participant two also described her daughter's time in hospital, and how she would spend her nights sobbing because she would just want to be well and to be able to go home again. Participant three also recalls her daughter crying during her stay at the hospital as well.

From a parental perspective it was hard emotionally to get their head around the types of medication that their child needed to take. *“you need to get your head around pumping your child full of drugs, you have thoughts about the drugs hurting your child but there is nothing you can do because you know they need them. At night you feel sad and worry about how she will grow up and deal with what could happen.”* [Participant one].

The findings of the current study are not surprising given other studies that have focused on depression and chronic illness. Individuals who have been diagnosed with a chronic illness are more likely to develop depression than healthy others (Bokemeyer, et al., 2013; Boschert, 2006). It could be argued that individuals who have IBD develop sadness such as that described above because of the chronic pain they experience, but as well as this they also have to come to terms with not being able to join in with peers or siblings at certain times because of the pain. Experiencing a loss of a normal life for a period of time is likely to impact their overall mental well-being.

The mannerisms of the participants, while describing their child's sadness was significant in that the researcher could visibly see the pain that they felt in relation to their child being much sadder. The mothers would look down; change the tone in their voice to being lower and sadder in themselves, as well as taking longer pauses after describing these changes that they could visibly see and notice in their child. These mannerisms could be described as empathy, in that the parents in a subtle way were demonstrating characteristics of sadness themselves, perhaps with no intention or awareness of doing so. Another likely explanation is that they were re-experiencing some of the feelings that they had experienced during these tougher times and there were memories and experiences that they were remembering that were not fond ones.

Anger. Feelings of sadness and anger are present in individuals with IBD due to the chronic nature of the disease and at times the participant's inability to participate in

activities or attend school with their peers. These emotions have been identified and replicated in many studies. This study supports prior findings with most individuals displaying some form of sadness or anger. Previous research mainly focuses on depressive symptoms as a co-morbid illness with IBD. While this has been taken into consideration for the current report, the researcher felt that anger also was an appropriate subtheme for these participants given the behaviours explained below.

Individuals naturally compare and liken themselves to others of similar ages or peers and produce these feelings as they become aware that they are unable to perform as they once had, or like their peers are able to. These feelings and emotions support previous research of low mood and depressive symptoms, the current study was able to capture these feelings through areas such as withdrawal from peers, being happier to spend time alone and parents noticing their child just seemed sadder. Many of the children in the study were too young to gain a formal diagnosis for depression, and much of their symptoms were not severe enough. However, this should be an area that is closely monitored by the medical professionals in order to provide support to families and children should they require it in the future. Many of the situations that the children are faced with are challenging and in many cases they are faced at times with a debilitating illness that restricts their abilities to participate in normal daily life, they are also dealing with chronic pain and symptoms that are often not able to be fully managed by medication. For most of the participant's anger was an emotion that was prevalent, parents would describe the way their child would act in an unrecognizable way. Participant 2 talked of the shock of seeing her daughter in a 'rage'. She describes how it was not something they had considered needing to deal with when they first got the diagnosis, she then talks about how it was necessary to sit down and discuss how they would approach her moods;

"Her mood swings were a huge impact on us as a family, at times she would get into quite a rage which was a huge shock for all of us. Her siblings found it particularly hard walking around on egg shells all of the time. We have managed that now, my husband and I had to sit down together and discuss how we would deal with her anger."

As well as sitting down with her husband, it was also important for participant two to sit down and talk to her other children;

“They had done nothing wrong and she would get really angry. We had to sit them both down and talk to them and to try and explain that she is probably feeling angry because they don’t have what she does. She sees them do things that she would like to be able to do and can’t.”

This anger was also evident in participant one’s story; she also describes her own anger not just that of her daughter;

“The steroids changed her, they changed her from a beautiful little girl into an absolute monster. She would cry and scream, she didn’t want to take her medicine and she would just spit it everywhere.... Sometimes it felt like a mix of emotions, you were upset but you were also angry and frustrated because you just wanted your child back

Another theory could be used to speculate over the anger that individual’s experience. Research shows that depressive symptoms can at times be displayed as anger or irritability (Boschert, 2006). Many of the children in the current research were very young and displaying outbursts of rage and anger, it is possible that the physical actions are being confused for anger rather than depression or sadness. Because the participant’s children were in some cases quite young, it is possible they were not able to verbalize exactly how they were feeling.

Alternatively, the anger that the children were displaying was a symptom directly relating to the medication that they were taking, much like participant one theorizes. Given the young age of the children in the study and the developmental stages that they were going through there is a possibility that the medication impacted this to cause the ‘rage’ and the anger that was displayed in these children.

Most of the parents in this research described a time that their child showed strong emotions of anger, or in some cases rage. During these explanations you could visibly see from their expressions and their body language how difficult this behaviour was to manage at the time that it was occurring. It was evident that this was an area that many of

the participants would like to not remember, and it had been extremely hard to see their child change visibly as well as changes to their behaviour. Participants demonstrated this in ways such as shaking their head slowly while recalling the awful period of time it was. Other behaviours such as emphasizing words in their sentences, this was for words that described their child's behaviours such as one participant describing how her daughter became a 'monster'. This emphasis made the researcher understand just how difficult this behaviour had been for the families, and from the descriptions above it became clear quickly that it was the whole family that were affected.

Resilience. Contrasting to the negative effects on the child's temperament, all of the parents described positive traits that they believe their child has developed since being diagnosed with IBD. This focus on positive outcomes of chronic illness is a relatively limited area in the research. Described as the individual's ability to bounce back or to adapt when faced with a challenge or adversity (Fergusson & Walker, 2014; van Loon & Visentin, 2006), resilience was seen in most of the children from the study. Collectively the traits that are described in the children as well as their families resemble resilience, making the children more determined and in some aspects more outgoing than previously. This could be a combination of personality traits as well as the supportive, caring and loving homes that all of the children were being raised in. Each child and each family have adopted their own unique ways to deal with the adversity in their lives and to come up with strategies for ways to cope. These strategies were subsequently seen as resilience for the purpose of this study, however, this term was not explicitly used by the parents during interviews, and this was the interviewer's interpretation of the children's behaviours. Participant one was the first parent to acknowledge and describe the trait in her daughter;

"She is very good at doing things herself, she is quite tolerant of a lot of things. And I think that it has made her more determined".

Participant two also describes her child's ability to spend a lot of time on her own;

"She is more able to be on her own than she was before."

Participant three had the eldest child with IBD, she stated that she was able to notice resilience as a change in her daughter;

“She tries everything now; she will give it all a go. She will sign up for everything that she couldn’t do last year and didn’t have the confidence to do. I think it was because she was denied things, it has made her seize the day.”

The body language of one participant came as a nice surprise to the researcher, participant three began to smile and her speech became uplifted throughout the description she gave of her daughter now. She spoke with pride about how her daughter now “gave everything a go” and took every opportunity that she could, given she had not been able too during the 12 months previously. The researcher was surprised by this positive outcome of the illness for this family as well as some of the more positive aspects that the other participants explained. It could be surmised that the supportive and loving environments that these children were being raised in helped to foster the resilience that was shown in these children; both of these characteristics in a family environment have been shown by research to be protective factors when it comes to building resilience in children (Fergusson & Walker, 2014; van Loon & Visentin, 2006)

Guilt. Each parent spoke of guilt, specifically guilt around how their child came to get the disease. For each participant this emotion was prevalent through the diagnosis phase of their journey, when perhaps their knowledge and understanding of the disease was limited. This finding was not supported by research, which is surprising given this was prevalent in almost all of the parents who were interviewed. For these participants the ‘unknown’ lead to them questioning themselves, and searching for answers as to why their child has IBD from their life style, their pregnancies, and their genetic make-up. For example, participant one noted;

“You begin to go through a mix of emotions, you ask ‘why them?’, you blame yourself, ‘what will the future hold for her?’, ‘has she got it off me?’”

This guilt-based perception seems to have resulted largely from the lack of knowledge surrounding IBD, many participants had heard of the disease before but did not have an

understanding of it. As well as this, the number of diagnoses in childhood is incredibly low. However, such diagnoses are becoming more common but because of the low number of diagnoses there are many cases of trial and error with the treatment of the children (Benchimol, et al. 2009). For one family, limited experience treating IBD in a child so young could have influenced the feelings of guilt in the early stages of diagnosis. Participant four recalls;

“Because he was so young, mostly what I would feel is what did I do wrong? I would question my pregnancy and my birth, but he was born by C-section, and lots of babies are born that way so it couldn’t have been that. Once we figured out what it was and that it wasn’t anything to do with me I soon got over it and stopped feeling sorry for myself.”

“The doctors didn’t know how to treat IBD in a child so young, they had only 3 known cases in Australasia in someone so young, so they just treated him the same they would an adult but on smaller doses of the medication”.

Guilt was often associated with the effects on siblings, a child with such a chronic illness requires much attention and often at times limits the activities that a family is able to do, and three of the four families spoke indirectly of the guilt the mother felt at times when they were required to stay at home with their sick child. Participant B reflected this clearly throughout the interview;

“Our eldest son told us that her illness had taken over our lives. We have taken a step back and thought there is only so much we can do to try and control it [IBD], there obviously had to be a change in our family, and this child had become a bit more of a focus but we now try and give them all the same attention”.

Participant one had a similar experience with their eldest son;

“Our eldest son was very quiet about it all really. But one day he spoke to our neighbour and said that he was really upset and worried, he hadn’t said anything to us because he didn’t want to put the extra stress on us. It has been hard; it hasn’t been easy.”

Research shows that it is common for siblings to display concern for their sick brother or sister. They lack understanding and knowledge about what is going on and often they have thoughts around their sibling dying or never returning home (McGrath, 2001; Williams, et al. 2009). While being concerned for their sibling might be perceived as a positive trait for a sibling to possess this can lead to less adaptable characteristics such as internalizing their feelings, and in the case of the child mentioned above not talking to their parents about how they are feeling. This in turn may lead to the parents displaying guilt as they realize the impact on their other children.

This guilt in relation to the parent's other children was a common theme in this study, however was not something well documented in other research on IBD, perhaps due to limited research on children and their families in this area. It is easy to see and understand how an ill child can consume a lot more time and resources than the parents have previously given. Unfortunately if one child is requiring more attention, then it might not be possible to spend as much time or attention as once had been placed on the other children. This in turn can lead to and has been demonstrated in this small study that the siblings of the sick child can feel like they are not receiving the attention of their parents, as they had once received. Once parents become aware of this then they feel guilty because their time and attention has been consumed by the sick child and the other children in the family have suffered. Parents then struggle to find an equal balance between their sick and their healthy children stretching their resources much further.

From reflection of the families that were interviewed, as well as analysing their transcripts and developing a greater understanding of their journey the researcher can surmise that these feelings of guilt related to the uncertainty and the unknown that followed diagnosis. The parents were coming to terms with a lifelong chronic diagnosis of their young child, and trying to get their head around what in fact IBD was and how it was likely to affect their child's health, and their future. It is likely that the emotions of guilt were present while they were searching for these answers, and coming to terms with what their IBD journey might look like. At the beginning of their journey they were uninformed about what IBD was, so feeling guilt about pregnancy or questioning if it was genetic in nature is referring back to things that are familiar, or common to them, and

they are drawing on all information about other common illnesses and the way that they can develop in individuals.

The previous research discussed in the literature review talks about the loss of power and influence that parents have when it comes to decision making and treatment course (Miles, 2003). This power is not completely eliminated however it is significantly reduced. Through reflection the researcher questions this vulnerability and the feeling of guilt that the parents have displayed and whether there is a relationship between the two. It might be possible that the feelings of guilt could also be attributed towards not being able to help their child and to make them better which in normal circumstances would be the parents' responsibility. Relying on someone else to provide that care and to present the parents with a choice about differing options could produce guilt.

It was obvious to the researcher that the parents in this research had at the time of diagnosis really questioned themselves and felt an element of guilt surrounding the illness that their child had. During the interviews when the participants were retelling this part of their journey the mothers would pause a lot, as if to reflect on the questioning again. They would also change the tone and speed in which they were talking, as if to re-ask these questions. It was not an area of their journey that they went into much description about. The researcher wonders if this was perhaps a sign that this was a stage that they had overcome through their own research and their journey so far.

School. School and preschool was a factor that was impacted greatly by the wellness of the child. All participants reported that when their child was going through a bout of chronic illness that they would spend a great number of days off school feeling unwell, and be unable to participate in any other activity. This situation has the possibility to severely impact on a number of areas of development, especially socially, and academically. The specific impacts on a child's school life were not well documented in previous research; rather there were specific focuses on socialization and peer relationships with no notable research that focused on academic outcomes. Owing to this the researcher has drawn on data from the current study as well as previous research to draw conclusions about the effect on academic development.

Difficulty forming and maintaining relationships. The ability to form and maintain relationships with peers or other adults at school was impaired for these children. There are a small number of studies that support the findings in this study whereby the children had noticeable impacts to their socialization with others (Nicholas, et al. 2007). Spending such high numbers of days absent from school makes this hard and in some cases hard to achieve. Participant 3 talks about her daughter's diagnosis coinciding with her starting a new school;

"She had just started at a new school where she knew no one. She didn't have the chance to meet new friends and to make real friendship's because she just wasn't at school enough for this to happen. The girls who she did become friendly with didn't understand, it's not exactly something that a young girl wants to share with their friends, they just thought she was bunking. She just didn't get a chance to form relationships like the other girls did."

Supplementary to a study conducted by Nicholas et al. (2007) the participant above found it hard to join a friend group because the ability to participate in activities healthy children could do, and even as simple as attending school on a regular basis became much more difficult. The reduced contact with peers became problematic for the child in that they could not form friendships and identify themselves with a particular friend group like the other students at the school.

Participant 2 describes her child's fear of going back to school after having so long absent;

"She struggles socially now; she is quite fearful to go back to school. We have had meetings with them [the school] about how she will be reintegrated back into the classroom because she has had so long off this year."

Participant four makes an interesting point, *"We would get invited to functions and we would have to say, thank you that would be great! But we will have to let you know on the day."* While this was not mentioned to the researcher as a negative or a complaint about their child's illness, the researcher thought that it was valuable to add this point in from a

parent's perspective in maintaining relationships. Due to the uncertainty surrounding IBD, and the unpredictability of when a flare up might occur it is not always easy for these families to plan ahead. During these times when the children require more care it might restrict the parent's socialization with friends or family and limit their ability to maintain the relationships that they previously had. While adult relationships differ somewhat from children's it is important to note that relationships the parents have outside of their immediate family can also be directly affected.

Peers of children with chronic illness often lack understanding of what they are going through. It was apparent that the participants in this study had only told select people about the illness their child had. Reasoning behind this seemed to commonly be because the illness was not 'glamorous' and it could become 'embarrassing' for the child. It would be interesting to view the outcomes of individuals and their socialization and peer relationships when people are aware of the difficulties that they are faced with. This then gives people the chance to understand and to empathize with them, rather than to criticize and to make assumptions about why individuals spend much of their time absent or are unable to participate in certain activities.

One participant talked about her daughter's difficulty forming friendships at a new school she went to because of the amount of time that she spent absent. Throughout her description of this it was visible in the way she spoke and recalled her struggle at a new school as well as the facial expressions that this was a difficult and somewhat painful time for this family. Describing the difficulties they were faced with when peers didn't understand why she would spend so much time absent from school the participant's voice wavered and became shaky. From the parent's perspective it was obvious to the researcher it was hard when a child was so ill. When they were well enough to participate in normal activities such as school they were unhappy and perhaps didn't quite fit in.

Academic Difficulty. Difficulty with school work was an aspect not covered in the literature, perhaps due to the more medical focus of IBD research. However, it could be surmised by the amount of time absent from school that this could negatively impact the child's academic ability. One participant talked of the academic struggle that her child

experiences and was the only participant that reported this issue. This child also happened to be the only male in the research, and was the youngest when he was diagnosed. The low report rate of this difficulty is surprising given that all children had considerable periods of time absent from school and it would be worth investigating further in future research. Participant four talks about her son's academic performance;

"He is nearly 12 but is operating at an 8-year-old level in all areas, school work, behaviour and conceptually. We don't know why, but have many things that it could be pinned on. Did the steroids he was on stunt his brain growth? Was it because he missed so much school? Or because he has physically developed so slowly has his brain developed slowly too?"

"He is now reading at his age level; he has finally caught up but even that is probably quite low for his age. He is terrible at spelling, can easily read it but if you can't write it back down then it's really hard. He just doesn't have the mechanisms to work it all back out again."

As well as the learning difficulties participant four speaks about the co-morbid learning disorders that her son is encountering;

"We have worked out that he has auditory processing disorder, so that means that what he is hearing is not being processed and everything he learns has to be taught again the next day."

"He shows that he has tendencies of mild dyslexia and autism, but when he has been tested he doesn't have enough traits to be diagnosed, so really he just has Chron's [disease]. Because he doesn't test for these learning disorders he only qualifies for three quarters of an hour with a teacher aide, which is hard on him because he really needs someone in class with him to help him do his work. But the trouble with that is they are worried he will become reliant on people doing things for him."

As participant four has explained and due to the characteristics of her child within the study (being the youngest diagnosed, and the only male) it is hard to draw conclusions

from this outcome. However, participant four makes some valid points about what could possibly cause these issues that he is faced with, such as the medications that his is required to take, the fact that so much school was missed, was this something that would have happened anyway or is it a combination of all or some of these factors?

An observation of this participant was the determination and commitment she showed towards improving her son's academic ability. This became evident in the way she was telling her story; her voice showed power and demonstrated taking control of the situation. During the interview this participant became almost excited about explaining how they are facilitating their son to get him back up to speed with his school work. Although she described some negative impacts of having extra help and support such as the financial toll, it was apparent that this was something that they as a family were very willing to do for their child and they were excited by the fact that they had noticed changes in their son's ability.

Emotional toll on family. Having a child who requires a lot of medical assistance and in turn a great deal of attention, has the ability to take its toll on all family members. Much of the research done in the past has had a focus on how family functioning can help to support and facilitate a child with chronic illness. The data that was collected from this study focused more on how the sick child impacted on other members of the family. Watching a child or sibling suffering immense pain, the inability at times to participate in many activities, and trying to understand and deal with the illness can cause difficulties among other family members.

“Emotionally it did take its toll, and it still does every now and then” participant one recalls, *“sometimes you felt a mix of emotions, you were upset and angry and frustrated because you just wanted your child back. Sometimes it was too hard, you just wanted to curl into a ball and say enough is enough. That’s when you needed the emotional support, but you didn’t have it.”*[Participant one].

Many of the participants spoke about the “emotional rollercoaster” they endured and are still enduring throughout their child’s illness. Participant Two talks about the impact she has felt becoming a caregiver for her child;

“you have to take on the role of caring for your child, and that is fine because that is our job as a parent but it is very different to the role that you are typically used to. It has had quite an impact on me because she has become very reliant on me. Every day is as it comes, if she is not well enough to do something then I am not able to do what I have planned.”

“You go through a mix of emotions [after the diagnosis], you have a lot of questions about the prognosis. Then you have to try and get your head around the illness, what they are going to do to help her. You soon realize it’s not as simple as a change of diet. The unknown information is hard, like how bad is it going to be? Will she need operations? They are all things that the doctors can’t tell us.”

Participant three described her views on the different ways things like this affect individual people, for her, her eldest daughter benefited from the support of a psychologist;

“You don’t realize how it is affecting different people in the family. Because she never spoke about it we didn’t realize she was finding it hard. As soon as she spoke to her [psychologist] she just broke down. What would have happened if no one came to talk to her?”

From a parent’s perspective they have to try and deal with the fact their child has a serious illness and help them, but they also need to come to terms with it themselves, *“it is tough getting your head around having a child who has an illness that is permanent, and there forever, it’s not an easy or a smooth road”* explains participant three.

Participant one recalls what it was like for their other two children trying to understand and deal with their sister’s diagnosis, this time was described by most of families similarly;

“It’s a complex thing and you can’t give them straight forward answers because you don’t have them. It was hard to try and get them to understand why she was behaving the way she was and why you suddenly couldn’t touch her stomach. It was hard.”

“Our eldest daughter found it hard when she was in hospital, all the focus would go onto her [sick daughter]. The whole house would revolve around her. She knows it has to be that way but it does affect them” Participant Three recalls.

Although families are faced with many negatives when it comes to having a child with a chronic illness, one mother reflects on a positive that has occurred for her family;

“It has really strengthened us; we now appreciate a lot of things. When you are suddenly denied things you learn to really appreciate what you have and what you are able to do”.

An interesting finding of this study was how members of extended family of two particular participants found it hard to understand the severity of the illness, and generally did not grasp the seriousness or the extent of disruption that was caused to the immediate family.

“They didn’t understand the impact on her or on us as a family. They had heard all the medical stuff but they weren’t actually here to see us deal with all the other stuff we had to deal with. They couldn’t understand why it couldn’t just be fixed, they hadn’t had to deal with all the other stuff that goes on with it like the change in mental well-being and her moods,” described Participant Two.

“Because it’s not a very talked about illness, people don’t understand the impact until you actually tell them.” [Participant Two].

Participant Three stated that *“the wider family don’t seem to be as in touch with what’s happened”* she described some frustration around the need to keep telling people things that seemed obvious to them but other family members didn’t seem to understand or get it.

The effects IBD has on the families in this study directly relates to how the families had learnt to cope with the illness, how other family members had managed with the illness as well as outcomes that might have surprised individuals such as strengthening their family. In partial keeping with previous studies that looked at the family unit as a whole, all participants in this study came from strong and supportive families. This protective factor is likely to have provided a positive element to the families during a tough time, being able to openly discuss and talk about important factors. All families had included siblings in the process, providing age appropriate information to the siblings about what IBD entailed, this meant that there were no secrets and siblings were able to try and understand and empathize for their sick brother or sister. It is also possible, but hard to surmise, that the strong supportive family units were able to protect against any adverse psychosocial or psychological effects for the child. Mild forms of both psychosocial and/or psychological issues were present in all participants, according to previous research this strong family bond could have facilitated the severity of these effects.

During the researcher's interview one participant became tearful, this very clearly demonstrates the emotional toll that having a child with a chronic illness has on parents and families as a whole. The emotional distress became present when she began to recall how sick her daughter had become at one point of their journey, an interesting point to consider is throughout these interviews parents were describing and talking about things that had been very tough and at times emotionally draining for them. It is possible that they had not reflected back on their journey in the depth that they were encouraged to do during our interviews together. Remembering the details of her daughter at her sickest is likely to have been the first time the participant has remembered small details and really thought about it, as she even made the comment that "*the brain does amazing things to forget the bad things*".

Divided family. Divided family was a term used by one mother in relation to the fact that most of the families involved in this research would often end up doing activities as separate halves due to their sick child being unable to participate planned activities and trips. Much of the time it was the mother who stayed with their sick child, this impacted the other children in the family as well who sometimes couldn't understand why their

Mother wasn't able to do things with them anymore. It also played its toll on parent who was staying behind or being at home with the sick child;

"My husband had to be off with the others so I had to be alone. It was a juggling act, when you needed the emotional support but you also knew that the other children needed their Dad to be at home with them. You felt very alone, sometimes when she was in hospital I would get very upset and it was very traumatic."

All families interviewed had very little or no immediate family supports in their given locations. Three families had many of their supports overseas, and the remaining family had a few members in the same city but had grandparents in another main centre. This alone was isolating and dividing for the families, they felt that the other family members did not understand the seriousness of what their child was experiencing, as well as in some cases not having the emotional support that they would have liked from them.

"We only have me and my husband here, the rest of the family is overseas so it made it more traumatic. We didn't want to worry them when she was first diagnosed so it took us a long time to talk to them. There was nothing that they could do from over there, so we took a while to figure things out before telling them the news." [Participant One].

"There has been a change in our family, this child has become a bit more of a focus for us but we try and give them the same amount of attention. It's hard though because if she is sick and we have planned to be away for the weekend or to go out together as a family then one of us has to stay behind with the other children, we have become divided as a family." Participant Two recalls what it is like not only for them as a family but how her daughter must be feeling about not being able to participate in the planned activities; *"She is on the outer and probably feels like she isn't part of the family all of the time."*

This finding has not been presented in any previous research, this is an interesting point given the difficulty the families were faced with in trying to keep life normal for their healthy children as well as provide the care that was needed for their sick child. This finding is unfortunately something that is not easily preventable given the number of

admissions and length of time that some of these children spend in hospital and given their ages it would not have been appropriate for the parents to leave them to be alone.

Another interesting point would be to monitor the strain that being a 'divided family' has on the individuals involved, there would be many factors that would influence the functioning of a family and could potentially involve some negative outcomes. The attachment or relationship that the parents have with their healthy children could be compromised due to the amount of time that is required to care for the sick child. A further consideration could be the stress of having a sick child and spending a lot of energy and time caring for them might have on the relationship of the parents. The sick child could have a reduced ability to maintain healthy relationships with their siblings and might develop feelings of envy or jealousy over not being able to participate in activities that they are able to. Alternatively, this jealousy could be displayed by the healthy siblings in relation to the sick child gaining more attention or time with one or both of their parents.

Financial Stressors. Most families in this study were affected financially by their child's diagnosis and illness. In most cases this wasn't due to paying for things such as medication or treatment but rather a parent, in all cases in this research, the mothers, having to give up work owing to spending too much time away at home caring for their sick child. Participant One explains;

"Financially it is hard. I had to give up work because I had a sick child at home. And we worry about my husband taking too much time off because we still have bills to pay. But sometimes he needs to take time off, his work have been very good and understanding about it all really."

Participant Two speaks of a similar situation;

"I had to give up work, I was having so much time off work that I just couldn't keep taking time off anymore."

Participant Three was in a different situation not being in employment at the time of diagnosis but throughout her interview she makes a comment about having a job;

“There was no way I could work. It would have been very different if I had to work. I was able to stay with him in the hospital, he was too young to be there by himself.”

As well as having to give up work, the families were faced with other financial burdens due to lacking resources or other services that they wanted to access that wasn't funded or offered as treatment for their child. Participant Three opted for a speech language therapist to assist her child by teaching him the basics again, *“we have a speech and language therapist teaching him the basics all over again and that's \$80 an hour. And we have got to pay for that, we have to find the money to pay for it because we have seen a huge difference in his school work already.”*

In the early stages of her child's diagnosis participant three was living overseas in a remote rural town, the closest hospital was a reasonable drive so the family *“ended up having to rent and then buy an apartment close to the hospital because we spent so much time there”*.

Participant Two speaks of taking things into their own hands;

“We took things into our own hands, we have decided to try alternative medicines, they are working but it won't cure it but we think in a combination it could help. We have also taken her to a private psychologist that we pay for ourselves. There was one offered through the public system but she was going away on maternity leave and the wait was too long between sessions. I think kids need consistency.”

Participant One talks about the hidden financial costs;

“Financially it is really hard, even things like paying for parking the car. I was paying a fortune in parking money. One day we went in for blood tests, thinking that it wouldn't take very long at all but she kicked off. I couldn't leave her, and I had no one to come in to be with her. I thought that I was going to get a parking fine, I was a blubbing mess.”

Psychological Support. An interesting finding from this study was the lacking psychological support that the families felt that they had. This was an important finding given the research that suggests that comorbid depression and anxiety are elevated for individuals with IBD. There are small amounts of research that suggest psychological support should be available for the family as a whole so that they are able to facilitate the individual along their journey and to avoid siblings feeling ignored or left out.

Participant One suggests, “*there was a lack of psychological support at the hospital. You are not told where to go to get financial help or psychological help, you were given a pamphlet.*” She goes on to mention, “*you are not told about support groups, probably because there isn’t any*”. This mother in particular was very active in joining online support groups for IBD, where her and her family felt more supported by others who were experiencing the same or similar things. They were able to discuss things that had worked and that hadn’t worked.

Once her daughter had received the diagnosis and things with the medication and treatment were under control it was commented on that “*you are left on your own. Abandoned and that’s it.*” While there are clinics that these families attend and there is always a medical professional that the families can call this was the impression that participant one got after all the initial appointments were over.

Participant Two suggests that there is not enough “*overall care. Their [medical professionals] job is to keep the UC under control. In children they don’t take into consideration the mental toll it takes on them and that toll is huge*”. She also talks about in the initial stages of her daughter’s diagnosis “*We have done a lot of finding out for ourselves on the impact. There is no information of the mental impact on us as family. It would be great to have support groups for parents and for siblings so you can talk about how you have dealt with certain things.*” This mother did say they were told to go to a psychologist that was at the hospital, however, she was due to go on maternity leave for 12 months and the family believed that children should have a constant person and have more regular sessions than were offered so they went to a private psychologist instead.

Additional Findings

This research uncovered some information that the researcher deemed to be valuable findings that could contribute to future research or the care of children and their families in the future but that did not fit within the themes above.

Participant Three spoke about the difficulty her daughter had at school directly relating to ‘celebrations’. She said that at school celebrations all seem to be around food. It was a hard adjustment for her daughter because it is *“not until you can’t have it do you realize how much of our society revolves around food. When you take the food out of the equation is it quite hard to celebrate.”* This is an important factor to consider with some of the psychological effects that have been clearly demonstrated in the current participants. These exclusions that occur in daily life are likely to contribute to the feelings of low mood or depression and anxiety especially around social situations where the individual is faced with not being able to ‘fit in’ due to the inability to eat. This might also contribute to the individuals reduced peer and social relationships, as they might not feel comfortable visiting friend’s houses or joining in on activities in their free time due to this factor.

Participant Three also highlighted privacy issues they were faced with at their daughter’s school. They believe there were some issues around the school not telling the other students in their daughter’s classes or other teachers as to why she was absent so often and why she was unwell. The mother agreed that in some cases there would be circumstances where this wasn’t appropriate. However, they had communicated with the school their daughters’ circumstances and she thought that her efforts of communication had been impeded due to the lack of information sharing. This could be due to the nature of the illness, and some of the stigma or embarrassment that is associated with it, or this could be due to the fact that the school was unaware they were able to disclose this personal information and were closely following the Privacy Act.

A further notable finding in this study was that the only male participant in the current study was the youngest at diagnosis and had followed the most severe course of IBD, more specifically Chron's disease, out of all of the participants in the current study. This is noteworthy given that the literature search yielded results that suggested there was a higher prevalence of IBD in females and males, this has been consistent with the findings in the present study. Also of note is the fact that this child had had his bowel and colon removed, the only participant in the study to undergo surgery this serious. As mentioned in the literature this is also in keeping with previous research that states that male gender is a risk factor for needing major abdominal surgery, as seen in this individual. It should not be overlooked however that as this child was the youngest when diagnosed and the course of his illness was the longest. It may be that the length and the severity of the child's illness could have contributed to the removal of his bowel. It is hard to draw comparisons to the other participants given the relatively short length of their illnesses. It should also be noted that two of the female participants had had colon resections, again consistent with the findings of the study in the literature search.

Chapter Six: Discussion

The present study aimed to explore the experiences families encounter when children have been diagnosed with IBD and subsequently spent time hospitalized because of the illness. The research also aimed to contribute to the limited literature on the psychological effects and the experiences that families have when they have a child who has been diagnosed with IBD. This was done through the use of semi-structured interviews with four mothers who each had a child who had a diagnosis of UC or CD. A qualitative research approach was utilized, in that the mothers could share their own personal experiences as well as their families, of their IBD journey with the researcher. The study intended to take a psychological approach in order to add to research that has previously focused on IBD. It focused on interviewing the parents of the children who have IBD to ensure the reliability of the story that was being recalled, it was likely that the parents were able to provide greater detail and accuracy of the journey they had encountered, and to provide an overview of how the family as a whole was affected.

Seven common themes as well as a number of sub themes emerged from the analysing the data collected; effects on a child's temperament, guilt, school, emotional toll on the family, divided family, financial stressors and psychological support. The use of the IPA frame work ensured that the themes drawn from the transcripts were reliable and valid throughout the participants. The findings from the data will be summarized and discussed in this section. The limitations of this study as well as recommendations for future research will also be stated followed by a conclusion.

Insights from the Findings

There are multiple factors that may have influenced the findings of the current study, namely the duration and severity of IBD that the children had in the study, as well as the age of the child at diagnosis. Additionally, other external factors such as the family make up, the economic status that the family fell into, and the approach the child's family took to the illness and the treatment. Despite the multiple influences, the real life experiences that unfolded from these stories provided helpful insights that have implications for the health and well-being of these children and their families.

This research highlighted findings, which complement previous research, such as the participants experiencing changes to their temperament and emotional function as well as challenges at school relating to both academic and friendship difficulties. There were also insights gained that were unique to this study such as the financial stress that the families go through, lack of psychological support and the term ‘divided family’ that was used by one family but experienced by others. This chapter aims to offer insight into the findings discussed in the results chapter and present the reader with the limitations and future research suggestions.

Summary of Findings Related to Existing Literature

Theme One: Effect on child’s temperament

Anxiety, sadness, anger and resilience were four common behaviours or emotions that the participants in the present study described. They identified seeing these changes unfold in their children after they had been diagnosed with IBD. The children had developed avoidance behaviours towards adverse situations such as medical procedures or peer socialization; they had developed greater levels of sadness preferring to spend much of their time alone. Many children expressed anger, with parents describing behaviours such as rage or mood swings that were unpredictable and challenging to deal with for the rest of the family. Another finding in the present study is the emotion of anger; many of the participants in the current study were described as having a lot of anger since their diagnosis. This was something that wasn’t supported by previous research in the cohort that was being examined. This could be due to the fact that the emotion that they were actually experiencing were depressive symptoms but their age meant that they were unable to regulate or articulate the emotion that they were experiencing correctly. It can be surmised that this is due to the fact that they are suddenly unable to participate in activities or normal routines that they were once able to. To contrast these negative impacts of IBD on the children, resilience was a factor that many of the parents described seeing in their child. This characteristic was also present within the family unit as a whole; this was recognized by the researcher upon reflection of the data and the

interviews. These findings are consistent with previous literature that has found that IBD and in many cases chronic illness; due to the lack of psychological research on IBD, that individuals can be affected in many areas of their well-being.

Much of the research done with a focus on IBD has consistently discovered that individuals are at risk of developing an anxiety disorder or depression. This complements the current study and its findings (Ananthakrishnan, et al., 2013; Bannaga & Selinger, 2014; Biedel & Alfano, 2011). Interestingly there was little research with a focus on IBD that supported the finding of resilience in both the individuals and the families in the present study. However there are some studies that looked at children with chronic illness and found that a number of protective factors such as supportive and loving environments could facilitate resilience seen in children and their families (Fergusson & Walker, 2014; Kralik van Loon & Visentin, 2006).

Theme Two: Guilt

For the participants of this research the experience of guilt was something that they all encountered throughout their journey. Each parent described a time which consistently appeared after their child was first diagnosed when they felt immense guilt and questioned whether they played a part in their child's diagnosis. This was an interesting finding and worthy of further research as it is not mentioned in current literature. There are studies that supported this finding with reference to chronic childhood illness, and with a focus on the siblings on these children (McGrath, 2001; Williams, et al., 2009).

The guilt that they were experiencing was thought to be added to by the lack of knowledge around IBD, the families in some cases only learning of the illness from their child's diagnosis, and some having very few facts about the course or cause of the illness. The uncertainty and unknowns that surrounded the illness caused the parents to question themselves, and to find 'blame' somewhere while they were still searching for answers themselves.

This finding is of importance in this study owing to the chronic course that the illness takes and the significance of supportive environments to facilitate adaptive behaviours and outcomes in the children and families. To reduce the guilt that is felt the parents need to be well informed about the aetiology and course that IBD can take as soon as possible after the diagnosis.

Theme Three: School

A key finding of this research was that spending many days absent from school was found to have an effect on child's academic ability and peer relationships. Participants in this study spoke of their child's inability to maintain relationships with their peers; anxiety surrounding spending a lot of time at home and needing to reintegrate back into the classroom; or anxiety around spending time with peers outside of school because they might need to use the bathroom. Owing to the number of days the children spent off school one participant also described her child's academic difficulties and the additional help and support that he requires. This was consistent in the literature as a significant factor when it comes to peer relationships, as the individuals are unable to participate in activities with their friends and even things such as school become much more difficult (Nicholas, et al. 2007). Participants went on to explain that their children became almost fearful to go back into social situations and that they struggle socially because of the number of days missed from school. Unfortunately, no research relating directly to IBD and the academic ability of the children and how this is affected could be found during the literature search, but this is worthy of further research given that all of the children in the study had significant periods absent from school and only one parent reported this as a struggle.

Theme Four: Emotional Toll on Family

A central finding described by all participants in this research was the emotional toll that the illness had on the family as a whole. Discussions regarding the emotional rollercoaster families endured due to the changing role that the parents were faced with, such as also becoming their child's caregiver. As well as other concerns they had about the effects that IBD can have on their child later in life, and recognizing their other

children and how they have dealt with the illness and the effects on them personally. This finding supports the view of authors (Kratz, et al. 2009) who highlighted the challenge that parents are faced with when they are required to perform medical care for their child. This places large amounts of stress and responsibility on the parents, and while it keeps the children out of hospital and in their family home it can have adverse effects on the parents themselves which can then transfer into family life (Kratz, et al. 2009).

One participant reported how the illness had strengthened their family; this was something that the researcher could not provide supporting research for. The participant spoke of how they now appreciate a lot more things and appreciate the things that they are able to do, because they have seen their daughter be denied simple things such as food.

The disconnect that the families felt between their immediate family and their extended families was also highlighted. The families felt as if the extended families did not understand because they were not living with it first-hand. The participants struggled with the fact that other people thought the disease could be fixed with medication or surgery, but in reality they were dealing with a complex array of symptoms as discussed above. This finding was something that has not been captured in previous research and should be considered in future studies.

Theme Five: Divided Family

It seems relevant to remind the reader at the beginning of this section that there is no research that was found during the literature search that relates to the term “divided family” given by one of the participants. This relates to the family needing to act in separate units for things such as outings, sport events and even weekends away. Many of the participants explained how they would often need to remain at home if plans had been made and the diagnosed child fell ill. During this time, they felt very alone and at times felt like they had no support but realized that it was important for the other children to have some normality continue in their lives. This is an area that could significantly impact the emotional state of the parents and it would be important to focus on this aspect

during future research.

Theme Six: Financial Stressors

The financial strain that the families in this study were faced with was something that most participants talked about. During the literature search, financial strain was not something that appeared in any of the reviewed studies. This is surprising given the number of participants in this study that were required to give up working in order to care for their child. Many of the participants talk about the strain resulting from reducing two incomes to one, however, there were other interesting aspects to their experiences that caused the families financial strain such as purchasing additional or alternative treatments. These treatments were seen to be taking the place of missing support the family required from the medical professionals such as a more regular psychologist, or academic support such as speech and language therapy. The alternative treatments were chosen by one family as they believed this provided more holistic and all rounded care for their child so this option was additional to the care they received from the local hospital and specialists. Hidden costs were a surprising finding to the researcher in this study, with a participant talking about the parking and its expense around the hospital.

Theme Seven: Psychological Support

A common finding all of the participants in the study stated was that they felt that they needed more psychological support, especially for their child. Many participants talked about the lack of information regarding additional help or assistance that they can get for themselves and their child. It was highlighted during the interviews that the participants thought there was a lack of support groups and that they feel like the medical professionals do not offer overall care, they are just there to control the IBD.

This finding provides a rich understanding that there is a need for holistic care for the overall well-being of the individual and their families. There have been studies that suggest psychological support should be available for the family to help family members understand and facilitate the diagnosed individual with their journey (Drotar, 2006; Khanna, et al. 2015. Enhanced support in this area would provide the individual with

tools that have the ability to reduce some of the other themes already stated such as anxiety and depression. It would also have the ability to reduce the amount of emotional stress and symptoms that the children experience, as well as their families.

Comparison with previous research

There is a gap in the current research on young people aged 16 years and below who have been diagnosed with IBD, therefore, there is minimal research for this study to draw from. As a result, research focusing on child hospitalization regardless of the disorder was considered as well as IBD research that had focused on slightly older young people has been used to draw conclusions. Findings from the present study supported current literature on child hospitalization, as well as providing insight into how families deal with a longstanding chronic illness. By listening to the participants stories and honouring their experiences, one cannot draw definitive conclusion as each individual family is unique. As well as similarities to previous research, they also highlight some exceptions and these exceptions may be useful to consider for future research.

Age of the child at diagnosis

This study had a range of ages in which the children were diagnosed, this has provided the current research with a rich understanding of mutual challenges that individuals and their families are faced with when on their journey with IBD. It also begins to highlight some of the more unique challenges that individuals are faced with, such as schooling and peer relationship issues. The age of diagnosis also plays a vital role in the ability for the families to cope and to deal with the illness that they are faced with. Children who are diagnosed at a younger age are likely to normalize their illness, as they do not know life any differently. Once their illness has been managed effectively with medicine or surgery then they are able to live a life that they perceive as normal, they are pain free and once again able to enjoy the things that at times they are unable to do when unwell. Their parents' perceptions of this 'normal' is somewhat biased, as in most cases they have other children that they are able to compare and measure their ill child against. The parents are then in a position to worry and have concerns or questions about their child's future and

their ability to live a ‘normal’ life. This then becomes more of an issue for the parents than the child, as the child is unaware of aspects of their futures that might be affected, and as it has been normalized at an early age it might not become a problem.

Previous research has not mentioned this point specifically before but areas such as socialization and body image have been noted as becoming concerning for individuals who have IBD, which could be directly related to the age of the children or adolescents at diagnosis, these concerns are likely to be more prevalent in older children given they were not diagnosed at an age where this could be normalized. From this it could also be surmised that parents of children with IBD who show greater signs of stress or lack resilience are likely to produce more adverse effects because their child picks up on this and it becomes a worry for the child too.

Coping Strategies

The current study had surprising findings surrounding the resiliency of the children and families involved. This was an aspect that had not been captured well in other research, with the vast number of studies focusing instead on the medical outcomes and symptoms of IBD. All of the families in the current study showed well developed routines and methods of coping, and some showed surprising amounts of optimism and positivity towards their child’s illness. This positivity could be closely linked to the literature on parental adjustment and resilience that is shown within these individuals. Even though they have been placed in a position of adversity they were still able to display an element of strength for their child and to provide the positivity that promotes resilience within the child themselves.

Fatigue

Earlier researchers have found significant numbers of individuals who have been diagnosed with IBD who experience chronic fatigue (Pellino, et al, 2014). One study mentioned in the literature review of this report stated that up to 43% of patients with CD and 33% of patients with UC experience fatigue, interestingly this was a symptom that

only one participant touched on (Czuber-Dochan, et al. 2014). She stated that her daughter “*She doesn’t sleep very well. She can be really exhausted but can’t sleep.*”

It is hard to conclude from this statement if the IBD was causing her daughter to have poor sleep and to become very tired or whether it was due to her young age. It is also hard to surmise from the symptoms that the parents described and what the child was actually experiencing, if in fact it was fatigue or tiredness.

From previous research with focus on IBD it would be safe to conclude that the patients that have reported experiencing fatigue come from an older cohort, perhaps the children in this study were not of an age where they could report individual symptoms. Namely, during a bout of illness it could be unlikely that the participants were able to separate out the different symptoms they were experiencing such as pain and tiredness or fatigue.

Overview of the Findings

The findings presented and discussed above clearly show a number of similarities that are consistent with previous literature, such as emotional distress in areas such as anxiety and low mood. There are also a number of new insights that could greatly add to the medical professionals supporting families on their journey, these unique findings suggest that the family as a whole is greatly affected. This would suggest that a more holistic wrap around approach for them would be beneficial when a child is diagnosed with IBD. Interestingly the present study uncovered some differences to previous studies, such as the participants did not talk about fatigue, something that had been consistently found in adult data.

The findings in this study present an opening for future research to fill, there are numerous areas that could be explored further or in greater detail.

Researcher’s Journey

Throughout the interview process the researcher was continually surprised at how genuine and open the participants were about sharing their experiences and their stories. The information that was shared was at times very personal and private and the

researcher was a complete stranger who walked into their family homes to talk about this sensitive topic. It would be important to consider why the participants felt that it was important to share their stories and to be included in the research. It would be fair to conclude that a lot of the participants at times felt alone, whether it was because the lack of support groups, the small number of immediate family in the city in which they lived or because of the lack of family cohesion due to the sick child needing more attention or not being able to attend family activities. This feeling of being alone could have contributed to the families wanting to participate and to be heard; it was an opportunity for them to talk to someone who was interested in hearing their journey, what they find challenging and other experiences they might have had. This opportunity might have provided them with a sense of healing and a way of being able to process the journey that they are currently on. Another perspective could be that the participants want more awareness of IBD and wanted to share their experiences so that they are able to contribute to knowledge and understanding that other individuals have of the illness. It has become clear to the researcher towards the end of this study that the initial belief that the child being admitted to hospital would be the most significant impact on these families was not correct. This was a surprising realization considering the stress and impact that having a child admitted to hospital must cause families. However, it is now clear after conducting the literature search as well as the interviews and analysing the data that in fact the most significant impact on these families is actually living with this life long illness on a daily basis.

Acknowledgement of Participants

It is appropriate to acknowledge the participants in this study and the huge contribution they were able to provide towards this study. Many of the participants stated that they did not think they had much to offer, but it is clear from the results in this study that they were able to provide the researcher with rich data and insights that have not yet been touched on. Not only did they offer insightful thoughts and stories but they were also able to offer their precious time. It is from these families sharing their personal stories and experiences with the researcher that it is possible that they can contribute to the learning of the health professionals who are directly involved with this cohort of people. It would

be the aim from these insights that the health professionals can strive to improve the care and attention that these families and future families receive.

Limitations

IBD is an illness that has such varying different stages, from manageable to very chronic and severe. The recovery and treatment and also impact on these varying stages. A limitation of the current study is that this was not considered as part of recruitment. The different stages that families were at could impair their story telling, it is likely that the parent describing the journey that they had been on was impacted by the most recent events that had occurred, whether they were positive or negative. As a consequence, the information offered from these families is not generalizable.

The interviews were conducted with the mothers of the patients. This was not the intention of the study, but as the mothers either worked flexible jobs or had had to give up their jobs because of their child's illness it was more convenient to arrange a time to meet with them. Therefore, the stories that were being told were from the view of the mothers, who had all played a large role in the care, hospitalization, as well as continuing to parent other children and to maintain a family home. The role of the mother in all four families was very much the majority caregiver, this could tend to have led them to tell their story from a very different perspective to other family members who tended not to have such a hands on role.

In addition, the socio economic status of the families included in this study was all relatively similar. This could have enabled the mothers to care for their children in the way that they were able too; this study would need to be replicated over a range of socio economic statuses to highlight a range of issues that may be apparent across the social economic spectrum.

Another limitation was the relatively small sample size for the main study which means the results cannot be readily generalized to other families in the same situations.

Future research

This small study provides some insight into the experiences and ongoing care that families of children with IBD are faced with. However, there are several amendments that could be made to future research that build on to this body of knowledge. Future research could focus on the experiences from a child's perspective to gain a greater understanding of the experiences that they experience from the perspective of an individual who is directly affected by the illness. In some cases, their vocabulary or emotional knowledge may not be developed enough to grasp their own experiences. It might be beneficial however, to include emotion cards, to enable a response that they might have experienced throughout their illness.

To gain further insight into the experiences of families the view of other family members needs to be taken into consideration. This might include fathers, siblings, grandparents or other members of extended families that have supported the care of the child or family. As individual members of families all tend to be affected differently it would be appropriate to gain an understanding directly from them rather than a recount from one family member.

Future research could also look at a larger cohort of participants. This would ensure the data collected was comparable and increase the reliability of the information gathered and the analysis of this data. As the current study was one of the first to view the psychological effects in the child and families, a large cohort was not covered in this study.

The present study has begun to develop a story, and an overview of the experiences that are had throughout the journey of IBD diagnosis, treatment, and care in children under the age of 16 years. Leading on from this study, there could be more focus on certain age brackets. Given the variety of different developmental stages throughout the current study's age limit there is greater variation in how the illness affected the families and the patient. Future studies could better group the participants so they are able see differences as well as commonalities between age groups and different stages in life.

The present study looked at participants who were all currently at different stages in their disease. Future research could look at grouping participants who were going through similar stages for the purpose of gaining insight into that particular area of the journey. This addition could provide knowledge of experience and difficulties that occur during each phase of their journey.

Conclusion

The primary aim of this study was to gain insight and understanding into the experiences that families have when they have a child that has been diagnosed with IBD. This study aimed to take a psychological phenomenon approach to add to the previous medically oriented literature in this area. The results of this study suggest that the individuals who are closely involved with the child who has the IBD diagnosis are greatly affected in a number of ways. These include changes in family dynamics, as well as the development of psychological symptoms and limitations being put in place for family activities and outings. Further investigation is needed with a focus on the findings of this research to better understand how these can affect the families and individual psychologically. It is clear from this study that the participants were affected by a number of factors that occurred throughout their daily lives, such as anxiety, anger, sadness and sometimes disruption to daily activities. These factors and situations had the ability to limit the family and to cause more distress for the child. Given the significant increase in childhood diagnosis of IBD and the effects that this can have on many aspects of their well-being further investigation of the impact of living with a child with IBD is needed. It would be important in future research to gain a multidimensional insight into these families and to interview other family members as well to hear their story.

References:

- Alemzadeh, N., Rekers-Mombarg, L. T. M., Mearin, M. L., J M Wit, J. M., Lamers, C. B. H. W., & van Hogezaand, R. A. (2002). Adult height in patients with early onset of Crohn's disease. *Gut*, 51(1), 26-29.
- Ambert, A., Adler, P. A., Adler, P., & Detzner, D. F. (1995). Understanding and evaluating qualitative research. *Journal of Marriage and Family*, 57(4), 879-893.
- Ananthakrishnan, A. N., Gainer, V. S., Cai, T., Guzman Perez, R., Cheng, S., Savova, G., et al. (2012). Similar risk of depression and anxiety following surgery or hospitalization for crohn's disease and ulcerative colitis. *The American Journal of Gastroenterology*, 108, 594-601.
- Bannaga, A. S., & Selinger, C. P. (2015). Inflammatory bowel disease and anxiety: Links, risks, and challenges faced. *Clinical and Experimental Gastroenterology*, 8, 111-117.
- Barbezat, G., Poulton, R., Milne, B., Howell, S., Fawcett, J. P., & Talley, N. (2002). Prevalence and correlates of irritable bowel symptoms in a New Zealand birth cohort. *The New Zealand Medical Journal*, 115(1164), 1-8.
- Barriball, K. L., & While, A. (1994). Collecting data using semi-structured interview: A discussion paper. *Journal of Advanced Nursing*, 19, 328-335.
- Beidel, D. C., & Alfano, C. A. (2011). *Child anxiety disorders: A guide to research and treatment* (2nd ed.). New York: Routledge.
- Benchimol, E. I., Guttman, A., Griffiths, A. M., Rabeneck, L., Mack, D. R., Brill, H., et al. (2009). Increasing incidence of paediatric inflammatory bowel disease in Ontario, Canada: Evidence from health administrative data. *Gut*, 58(11), 1490.
- Bennebroek Evertsz', F., Thijssens, N. A. M., Stokkers, P. C. F., Grootenhuis, M. A., Bockting, C. L. H., Nieuwkerk, P. T., et al. (2012). Do inflammatory bowel disease patients with anxiety and depressive symptoms receive the care they need? *Journal of Crohn's and Colitis*, 6(1), 68-76.
- Bernstein, C. N., & Nabalamba, A. (2006). Hospitalization, surgery, and readmission rates of IBD in Canada: A population-based study. *The American Journal of Gastroenterology*, 101(1), 110-118.
- Blanchard, E., Schwarz, S., Suls, J., Gerard, M., Scharff, L., Greene, B., et al. (1992). Two controlled evaluations of multicomponent psychological treatment of irritable bowel syndrome. *Behaviour Research Therapy*, 30, 175-189.
- Bogdan, R., & Biklen, S. K. (2007). *Qualitative research for education: An introduction*

- to theories and methods (5th ed.). Boston: Pearson A & B.
- Boirivant, M., & Cossu, A. (2012). Invited medical review inflammatory bowel disease. *Oral diseases*, 18, 1-15.
- Bokemeyer, B., Hardt, J., Hüppe, D., Prenzler, A., Conrad, S., Düffelmeyer, M., et al. (2013). Clinical status, psychosocial impairments, medical treatment and health care costs for patients with inflammatory bowel disease (IBD) in germany: An online IBD registry. *Journal of Crohn's and Colitis*, 7(5), 355-368.
- Bolig, R., & Weddle, K. (1988). Resiliency and hospitalization of children. *Children's Health Care*, 16(4), 255-260.
- Boschert, S. (2006) Risk factors for depression identified in adolescent IBD. *Clinical Psychiatry News*, 34 (5), 48.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87-108.
- Chron's and Colitis foundation of America. (2016). *What are Chron's and colitis*. Retrieved from <http://www.ccfa.org/what-are-crohns-and-colitis/what-is-crohns-disease/>.
- Clarke, N. E., McCarthy, M. C., Downie, P., Ashley, D. M., & Anderson, V. A. (2009). Gender differences in the psychosocial experience of parents of children with cancer: A review of the literature. *Psycho-oncology*, 18(9), 907-915.
- Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (3rd ed.). New York: Pearson/Merrill Prentice Hall.
- Czuber-Dochan, W., Norton, C., Bredin, F., Darvell, M., Nathan, I., & Terry, H. (2014). Healthcare professionals' perceptions of fatigue experienced by people with IBD. *Journal of Crohns & Colitis*, 8(8), 835-844.
- Drotar, D., & American Psychological Association. (2006). *Psychological interventions in childhood chronic illness* (1st ed.). Washington, DC: American Psychological Association.
- Dubner, S. E., Shults, J., Baldassano, R. N., Zemel, B. S., Thayu, M., Burnham, J. M., et al. (2009). Longitudinal assessment of bone density and structure in an incident cohort of children with crohn's disease. *Gastroenterology*, 136(1), 123-130.
- Edward, K., & Welch, T. (2011). The extension of Colaizzi's method of phenomenological enquiry. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 39(2), 163-71.

- Engstrom, I. (1999). Inflammatory bowel disease in children and adolescents: Mental health and family functioning. *Journal of Pediatric Gastroenterology & Nutrition*, 28 (4), 28-33
- Ferguson, P., & Walker, H. (2014). 'Getting on with life': resilience and normalcy in adolescents living with chronic illness. *International Journal of Inclusive Education*, 18,(3), 227-240.
- Franck, L., Wray, J., Gay, C., Dearmun, A., Lee, K., & Cooper, B. (2015). Predictors of parent post-traumatic stress symptoms after child hospitalization on general pediatric wards: A prospective cohort study. *International Journal of Nursing Studies*, 52(1), 10-21.
- Freeman, H. (2004). Comparison of longstanding pediatric onset and adult onset chronic disease. *Journal of Pediatric Gastroenterol Nutrition*, 39 (2), 183-186.
- Gavin, L., & Wysocki, T. (2006). Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness. *Journal of Pediatric Psychology*, 31(5), 481-489.
- Grbich, C. (2007). *Qualitative data analysis: An introduction*. Thousand Oaks: SAGE Publications.
- Griffiths, A. M., Nicholas, D., Smith, C., Munk, M., Stephens, D., Durno, C., et al. (1999). Development of a quality of life index for pediatric inflammatory bowel disease: Dealing with differences related to age and IBD type. *Journal of Pediatric Gastroenterology & Nutrition*, 28, (4), 46-5.
- Griffiths, A. (2004). Specificities of inflammatory bowel disease in childhood. *Best Practice & Research Clinical Gastroenterol*, 18 (3), 509-523.
- Hägglöf, B. (1999). Psychological reaction by children of various ages to hospital care and invasive procedures. *Acta Paediatrica*, 88, 72-78.
- Hallstrom, I., Runesson, I., & Elander, G. (2002). Observed parental need during their child's hospitalisation. *Journal of Pediatric Nursing*, 17, 140-148.
- Hardt, J., Muche-Borowski, C., Conrad, S., Balzer, K., Bokemeyer, B., & Raspe, H. (2010). Inflammatory bowel diseases as multi-focal disorders: Results from a multi-regional survey on bodily and psychosocial problems in IBD patients. *Zeitschrift Fur Gastroenterologie*, 48(3), 381-391.
- Henderson, P., Hansen, R., Cameron, F. L., Gerasimidis, K., Rogers, P., Bisset, W. M., et al. (2012). Rising incidence of pediatric inflammatory bowel disease in Scotland. *Inflammatory bowel disease*, 18(6), 999-1005.

- Heuschkel, R. (2008). Inflammatory bowel disease in children. *Clinical Medicine*, 8(3), 297-298.
- Khanna, A. K., Prabhakaran, A., Patel, P., Ganjiwale, J. D., & Nimbalkar, S. M. (2015). Social, psychological and financial burden on caregivers of children with chronic illness: A cross-sectional study. *The Indian Journal of Pediatrics*, 82(11), 1006-1011.
- Kralik, D., van Loon, A., & Visentin, K. (2006). Resilience in the chronic illness experience. *Educational Action Research*, 14 (2), 187-201.
- Kratz, L., Uding, N., Trahms, C. M., Villareale, N., & Kieckhefer, G. M. (2009). Managing childhood chronic illness: Parent perspectives and implications for parent-provider relationships. *Families, Systems, & Health*, 27(4), 303-313.
- Lyons, E. & Coyle, A. (2007). Doing interpretative phenomenological analysis. *Analysing qualitative data in psychology*. London: SAGE Publications Ltd.
- Lemberg, D., & Day, A. (2015). Chron's disease and ulcerative colitis in children: a update for 2014. *Journal of Paediatrics and Child Health*, 51, 266-270.
- Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ: British Medical Journal*, 311(6997), 109-112.
- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach* (2nd ed.). Thousand Oaks, Calif: Sage Publications.
- Melnyk, B. (2000). Intervention studies involving parents of hospitalized young children: An analysis of the past and future recommendations. *Journal of Pediatric Nursing*, 15(1), 4-13.
- McGrath, P. (2001). Findings on the impact of treatment for childhood acute lymphoblastic leukemia on family relationships. *Child Family Social Work*, 6, 229-237.
- Miles, M. (2003). Living with illness: Support for parents during a child's hospitalization. *The American Journal of Nursing*, 103(2), 62-64, from <http://www.jstor.org.ezproxy.canterbury.ac.nz/stable/29744962>
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, California: Sage Publications.
- Moeeni, V., & Day, A. (2011). Impact of inflammatory bowel disease upon growth in children and adolescents. *International Scholarly Research Network Pediatrics*, 2011, 1-5.

- Möller-Leimkühler, A. M., & Wiesheu, A. (2012). Caregiver burden in chronic mental illness: The role of patient and caregiver characteristics. *European Archives of Psychiatry and Clinical Neuroscience*, 262(2), 157-166.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks: SAGE Publications Ltd.
- Murray, J. S. (2000). Understanding sibling adaptation to childhood cancer. *Issues in Comprehensive Pediatric Nursing*, 23, 39-47.
- Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: A qualitative examination. *Health and Quality of Life Outcomes*, 5(1), 28-28.
- Opheim, R., Fagermoen, M. S., Bernklev, T., Jelsness-Jorgensen, L., & Moum, B. (2014). Fatigue interference with daily living among patients with inflammatory bowel disease. *Quality of Life Research*, 23(2), 707-717.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, California: Sage Publications.
- Pellino, G., Sciaudone, G., Caserta, V., Candilio, G., De Fatico, G., Gagliardi, S., et al. (2014). Fatigue in inflammatory bowel diseases: Relationship with age and disease activity. *International Journal of Surgery*, 12(2), 60-63.
- Picci, R. L., Oliva, F., Trivelli, F., Carezana, C., Zuffranieri, M., Ostacoli, L., et al. (2015). Emotional burden and coping strategies of parents of children with rare diseases. *Journal of Child and Family Studies*, 24(2), 514-522.
- Popp, J. M., Robinson, J. L., Britner, P. A., & Blank, T. O. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing*, 29, 58-64.
- Qualia, C. M., & Bousvaros, A. (2013). Advances in pediatric IBD. *Current Pediatrics Reports*, 1(3), 206-213.
- Quinton, D., & Rutter, M. (1976). Early hospital admissions and later disturbances of behaviour: An attempted replication of douglas' findings. *Developmental Medicine and Child Neurology*, 18(4), 447-459.
- Reigada, L., Benkov, K., Bruzzese, J., Hoogendoorn, C., Szigethy, E., Briggie, A., et al. (2013). Integrating illness concerns into cognitive behavioural therapy for children and adolescents with inflammatory bowel disease and co-occurring anxiety. *Journal for Specialists in Pediatric Nursing*, 18, 133-143.

- Rottoli, M., Remzi, F. H., Shen, B., & Kiran, R. P. (2012) Gender of the patient may influence perioperative and long-term complications after restorative proctocolectomy. *Colorectal Disease*, 14, 336-341.
- Sanderson, I. R. (2014). Growth problems in children with IBD. *Nature Reviews Gastroenterology & Hepatology*, 11(10), 601-610.
- Shikhare, G., & Kugathasan, S. (2010). Inflammatory bowel disease in children: current trends. *Journal of Gastroenterol*, 35, 673–682.
- Skipper, J. K., & Leonard, R. C. (1968). Children, stress, and hospitalization: A field experiment. *Journal of Health and Social Behavior*, 9(4), 275-287.
- Smith, J.A. & Osborn, M. (2003). *Qualitative Psychology: A Practical Guide to Research Methods*. Los Angeles: SAGE.
- Sylvester, F. A., Leopold, S., Lincoln, M., Hyams, J. S., Griffiths, A. M., & Lerer, T. (2009). A two-year longitudinal study of persistent lean tissue deficits in children with crohn's disease. *Clinical Gastroenterology and Hepatology*, 7(4), 452-455.
- Sylvester, F. A., M.D. (2012). Bone protection measures in children and adolescents with IBD. *Inflammatory Bowel Disease Monitor*, 13(2), 51-57, Retrieved from <http://search.proquest.com.ezproxy.canterbury.ac.nz/docview/1314733458?accountid=14499>
- Sylvester, F. A., Wyzga, N., Hyams, J. S., Davis, P. M., Lerer, T., Vance, K., et al. (2007). Natural history of bone metabolism and bone mineral density in children with inflammatory bowel disease. *Inflammatory Bowel Diseases*, 13(1), 42-50.
- Van Manen (1997). *Researching the lived experience: Human science for an action sensitive pedaology*. Canada: Hignell Book Printing.
- Van Manen (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. USA: Left Coast Press Ltd.
- Wagtman, M. J., Verspaget, H. W., Lamers, C. B., van Hogezaand, R. A., (2001). Gender-related differences in the clinical course of crohn's disease. *The American Journal of Gastroenterol*, 96, 1541-1546.
- Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, 52(2), 167-177.
- Wertz, F. J. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York: Guilford Publications, Inc.

- Whelan, T., & Kirkby, R. (2000). Parent adjustment to a child's hospitalisation. *Journal of Family Studies*, 6, 46-64.
- Wilson, M. E., Megel, M. E., Enenbach, L., & Carlson, K. L. (2010). The voices of children: Stories about hospitalization. *Journal of Pediatric Health Care*, 24(2), 95-102.
- Williams, P. D., Ridder, E. L., Setter, R. K., Liebergen, A., Curry, H., Piamjariyakul, U., et al. (2009). Pediatric chronic illness (cancer, cystic fibrosis) effects on well siblings: Parents' voices. *Issues in Comprehensive Pediatric Nursing*, 32, 94-113.
- Wojnar, D., & Swanson, K. (2007). Phenomenology an exploration. *Journal of Holistic Nursing*, 25, 172-180.
- Zelinkova, Z., & der Woude, C. J. (2014). Gender and inflammatory bowel disease. *The Journal of Clinical Cell Immunology*, 5, 245.
- Zhou, H., Yao, M., Chen, W., Sun, M., Cheng, G., Chen, Y., et al. (2012). High prevalence of irritable bowel syndrome with poor sleep quality in children and adolescents in Shanghai. *Sleeping and Biological Rhythms*, 10, 179-186.

Appendix A:

Telephone: 027 2543 064
Email: rebecca.woolman@pg.canterbury.ac.nz



Appendix A:

Research Project for Families' experiences following their child's hospitalisation
for Inflammatory Bowel Disease

Information for Families

Dear

My name is Rebecca Woolman and I am currently studying towards a Masters Degree in Child and Family Psychology at the University of Canterbury. As part of my study I am undertaking research into families with children who have been diagnosed with Inflammatory Bowel Disease (IBD) and who have spent time in hospital for this disorder.

My aim in undertaking this research is to capture the real lived experience of families during and following the repeated hospitalisation of a child with IBD. This information will then provide a foundation of knowledge to health professionals and families in similar situations. This information can then be used to improve or change the quality of care and support that families receive when a child has been diagnosed with IBD and requires hospitalisation. This research is important to both health professionals and families in order to ensure that the support and care that is provided is appropriate and meeting the needs of individuals.

Previous research done with a focus on IBD has a very specific medical focus, drawing on the pain and management of symptoms in individuals, very few studies or research have focused on the psychological affects on individuals, even though it is well documented that patients commonly display psychological distress.

Telephone: 027 2543 064
Email: rebecca.woolman@pg.canterbury.ac.nz



I am interested in the experiences that families face caring for a child with IBD, during their stay in hospital as well as the ongoing care in the family home. The participants that are required for this study are a parent or caregiver of a child with IBD, other members of the extended family are also invited to contribute if they have spent significant amounts of time caring for the child.

Parents and/or caregivers will be required to take part in a semi structured interview which is expected to take 1 – 1.5 hours. The interview will take place in a mutually agreeable location.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public. To ensure anonymity and confidentiality, any information that is collected throughout the interview will be securely stored in a filing cabinet in a locked room and destroyed after the required time of the University of 5 years. Participants names and any other details that clearly identify the participants will be changed in order for confidentiality to be kept. A thesis is a public document and will be available through the UC Library.

You may receive a copy of the project results by contacting the researcher at the conclusion of the project. Additionally, the transcript of the interviews will be made available to you to give you the opportunity to amend or comment on the interview.

The project is being carried out as a requirement for a Masters in Child and Family Psychology by Rebecca Woolman under the supervision of Kate Reid who can be contacted at kate.reid@canterbury.ac.nz. She will be pleased to discuss any concerns you may have about participation in the project.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax 0800 2 SUPPORT (0800 2787 7678)

Telephone: 027 2543 064
Email: rebecca.woolman@pg.canterbury.ac.nz



Email: advocacy@hdc.org.nz

You can also contact the Chair of the University Human Ethics Committee by phone (03 364 2987) or by email: at human-ethics@canterbury.ac.nz

I wish to invite you and your family to participate in this study. You are able to withdraw from the study at anytime up until the time of data analysis.

If you agree to participate in the study, please contact the researcher to arrange a time to meet, at a location that is convenient for you. At this time it is possible to clarify any questions or concerns that you have before signing the consent form and agreeing to participate in the study.

Thank you for considering participating in this study.

Rebecca Woolman (Student Researcher)

Phone: 027 2543 064

Email: rebecca.woolman@pg.canterbury.ac.nz

Kate Reid (Supervisor)

Email: kate.reid@canterbury.ac.nz

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any concerns to

Address: The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch

Email: human-ethics@canterbury.ac.nz

Appendix B:

Telephone: 027 2543 064
Email: rebecca.woolman@pg.canterbury.ac.nz



Appendix B:

Families' experiences following their child's hospitalisation for Inflammatory Bowel Disease

Participation Consent Form

I agree that

- ☐ I have been given a full explanation of this project
- ☐ I have read the information sheet and have had an opportunity to ask questions about the study.
- ☐ I am taking part in this study at my own free will.
- ☐ I understand what will be required of me if I agree to take part in this project.
- ☐ I understand that my participation is voluntary and that I may withdraw at any stage without penalty.
- ☐ I understand that any information I provide will be kept confidential to the researcher and that any published or reported results will not identify me.
- ☐ I understand that all data collected about our family for this study will be kept in locked and secure facilities at the University of Canterbury and will be destroyed after five years.
- ☐ I understand that I am able to receive a report on the findings of this study. I have provided my email details below for this.
- ☐ I understand that if I require further information I can contact the researcher, Rebecca Woolman or supervisor, Kate Reid. If I have any concerns, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)

Telephone: 027 2543 064
Email: rebecca.woolman@pg.canterbury.ac.nz



I would like to receive a copy of the results from this study

Yes ☐ No ☐

By signing below, I agree to participate in this research project.

Name: _____

Date: _____

Signature: _____

Email address: _____

Appendix C:



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/76

20 August 2015

Rebecca Woolman
College of Education, Health & Human Development
UNIVERSITY OF CANTERBURY

Dear Rebecca

The Human Ethics Committee advises that your research proposal "Experiences of families after the hospitalisation of a child" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 11 August 2015.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L Macdonald'.

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Appendix D:

Canterbury
District Health Board
Te Pōari Hauora o Waitaiāra

Research Office Project ID
RO# 15170

Request For Locality Authorisation Form (Non-commercial/Non-government/Government Research Projects)

Instructions:

1. Complete the form.
2. Print the form and obtain approval/s from Clinical Director and Service Manager from the host department where the research project will be conducted.
3. The following documents **MUST** accompany your Locality Authorisation Form:
 - a. Ethics Approval Letter
 - b. Maori Consultation Letter
 - c. Source of Funding – e.g., contracts, email confirmation, proof of funding document
4. Send the completed Locality form along with the required documentation to Research Office, Level 5 Christchurch School of Medicine, University of Otago, Christchurch or send via email to cdhb.researchoffice@otago.ac.nz.
5. The Research Office will endeavor to process your locality within 5 working days WHEN ALL THE DOCUMENTATION REQUIRED IS RECEIVED.

RESEARCHER TO COMPLETE AND ATTACH ALL REQUIRED DOCUMENTATION

1. Staff

Contact Person/s: Email:
Local Lead Investigator Organisation (Employer)
Signature

Coordinating Investigator and Organisation
(If CDHB is not the lead site)

2. Project Details

2.1 Project Title/Protocol Number:

Families experiences following their child's hospitalisation and continuing care for Inflammatory Bowel Disease (IBD)

2.2 Timeframe of recruitment with CDHB

September – Early November

Research Office Project ID RO# 15170

2.3 Project commencement and conclusion dates (if applicable, copy answer from HDEC question a.1.4 in the box below)

Planned Start Date: 12/10/15

Planned End Date: 30/11/15

2.4 Brief Summary of the Project (if applicable, copy answer from HDEC question a.1.5 in the box below)

This study will capture the experiences families during hospitalisation and continuing care of a child with IBD.

Child hospitalization can be a traumatic and stressful time for all individuals involved. Despite medical professionals and the hospitals attempts to make a child's stay as comfortable and as stress free as possible, it is common for parents or caregivers involved to rate their anxiety levels far higher than the child during this time (Whelan & Kirkby, 2000). This anxiety can have detrimental effects on the child, the emotional contagion hypothesis explains this as the transference of emotions from the caregiver to the child, this happens without awareness of either individuals (Whelan & Kirkby, 2000). Underlying factors that cause a range of negative reactions in parents and care givers have been given little attentions but can cause additional adverse reactions such as; anxiety, depression, sleep disturbance and loss of appetite. These factors are not only present throughout a hospital stay but can affect the parents and family long after discharge when faced with factors such as consequent treatment that they may be required to administer (Hallstrom, Runesson & Elander, 2002).

IBD Inflammatory bowel disease (IBD) involves chronic inflammation of all or part of the digestive tract. IBD primarily includes ulcerative colitis and Crohn's disease. Both usually involve severe diarrhea, pain, fatigue and weight loss. IBD can be debilitating and sometimes leads to life-threatening complications. Children's lives can be significantly impacted by IBD, with many spending a number of days absent from school a year causing social and academic difficulties as well as attending many physician appointments or as many as 25% of children and adolescence needing emergency medical attention or hospital admission.

The identification of the issues and challenges that families are commonly faced with will allow a more complex and in-depth view of the individual encounters of this particular condition. Health professionals have the chance to benefit from findings of this research. With the information and knowledge that is provided it may be possible to improve the care and support that is offered to families in order to prevent some of the stressors that are present for the family during this time. There is a gap in the literature regarding the psychological challenges that families are faced with. Therefore this research project is important to undertake to help bridge this gap.

2.5 Describe procedures that will be undertaken by participants in your study.

☐ Within standard of care

☐ Outside standard of care (if applicable, copy answer from HDEC question r.1.1 in the box below)

Participants will be required to meet with the researcher for one session of no more than 90 minutes and take part in a semi structured interview. The location will be at a mutually agreeable location for both the participant and the researcher. The interviews will not take place in the hospital. Participants will have a chance to lead the interview themselves, talking only about experiences that they feel are relevant and are comfortable sharing with the researcher.

3. CDHB Resources Used

3.1 CDHB Participants- Recruitment Process and Number (if applicable, copy answers from HDEC questions a.6.2 and p.2.1 in the box below)

I have been in contact with Prof. Andrew Day who is supportive of this project. He will help with the recruitment phase, information and consent forms will be sent out to patients in his care or care of his team. Once the data has been collected and reported, I will present the results to Professor Day and his team.

No other CDHB resources will be used for this research.

3.2 CDHB Staff (names and occupation)

	Name/Department	Role in the Project
1	Prof. Andrew Day	Recruitment
2		
3		

4		
5		

Research Office Project ID	RO# 15170
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	Name/Department	Role in the Project
6		
7		
8		
9		
10		

3.3 CDHB Facilities (list specific location/s and department/s where the project will be conducted e.g., Burwood, Orthopaedic Dept.)

1	
2	
3	

3.4 Other Resources Required (e.g., Medical/Clinical Records, use of specific medical devices, etc.)

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4. Documents Required – THE FOLLOWING DOCUMENTS SHOULD BE SENT ALONG WITH THE COMPLETED LOCALITY AUTHORISATION FORM:

4.1 Ethics Approval* or Out-of Scope Letter (enter name of Ethics Committee, reference number and date of letter).

If Ethics Out-of-Scope letter is not available, Researcher should state the project is "outside ethics review" and sign and date

<p><i>* If the project has been approved by HDEC, please ensure to request locality on-line via the HDEC website. You will need to type in our email address cdhb.researchoffice@otago.ac.nz. Please contact RO if you need assistance in requesting Locality.</i></p>

4.2 Local Maori Consultation (enter date of letter)

Not required for this project as in consultation with the paediatric team and Prof Day, there are no Maori families with IBD, in the service.

<input type="checkbox"/> TKW _____	<input type="checkbox"/> UOC _____
<input type="checkbox"/> Other, please specify _____	

4.3 Source of Funding to cover all costs "outside standard of care" (attach proof of funding document e.g., contract, confirmation letter/email)

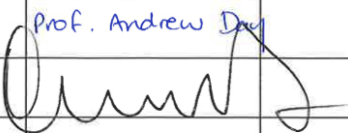

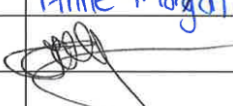
No funding is required.

4.4 Proof of Indemnity (if local PI is NOT CDHB or UO staff)

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RESEARCHER TO ORGANISE APPROVAL FROM RESPECTIVE MANAGERS

5. Approval From All Areas Where Resources are Accessed

	Department 1	Department 2	Department 3
Local Principal Investigator	Prof. Andrew Day		
Signature			
Clinical Director	Clare Doocey		
Signature			
Service Manager	Anne Morgan		
Signature			
Other Approving Manager Name			
Title			
Signature			

RESEARCH OFFICE TO FACILITATE APPROVAL FROM CDHB GENERAL MANAGER/S

General Manager sign-off

This research will take place in your hospital, do you approve it?

Hospital 1	Pauline Clark General Manager Christchurch Hospital Name:	 Signature:	8/12/15 Date:
Hospital 2	Name:	Signature:	Date:
Hospital 3	Name:	Signature:	Date: